

Winter 2006

## VOR History Project

VOR's History Project continues. See <http://vor.net/historystories.html> for details.

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

## President's Message

### Funding Effective Advocacy

by Mary McTernan, President



As the old year wanes and the new one fast approaches, people and their organizations tend to "take stock." We think about this year's accomplishments and our hopes for the future.

Early this year, VOR was blessed with the ability to hire two new employees. Tony Padgett is our new Director of Resource Development, and Larry Innis established a brand new VOR office in Washington, D.C. Both gentlemen have fit quietly and effectively into the VOR family.

Without the ongoing, dedicated financial support of the people most intimately impacted by the issues affecting people with mental retardation, VOR would not be celebrating these and other past accomplishments. Likewise, continued financial support from the families of the people with mental retardation we represent is necessary if VOR is to continue to provide the representative voice that we do in the Congress, in the courts, in the media, and in offices of federal and state bureaucracies.

If you have not yet responded to my annual Holiday Appeal letter, please be as generous as you can. Several members now pledge monthly gifts of \$20, \$25, \$50, or \$100, which is automatically charged to the members' credit cards. This is a convenient way to benefit VOR on an ongoing basis.

Whatever you can do to help, the VOR Board of Directors is grateful to each and

every member, for without your support there would be no VOR. And without VOR's advocacy, there would be no national voice in support of choice of residential options and services for our loved ones with mental retardation.

### Looking forward to 2007

We must be, and will be, prepared to go forward with greater energy toward our goal of responsible, reality-based planning for the wide spectrum of people with mental retardation with very specialized needs.

In 2007, Congress will reauthorize the Developmental Disabilities Assistance and Bill of Rights Act. This is the federal law that funds your states' Protection and Advocacy agencies and DD Councils. Although the shift in leadership in Congress will change the debate, Medicaid and Social Security Reform will continue to be discussed. Regulatory cuts to Medicaid by the Administration remain on track, despite significant bi-partisan state and federal opposition.

VOR will remain vigilant in the Congress and the Courts on your behalf in 2007 and beyond. When you consider charitable contributions during this holiday season, please think of VOR and all that we do on behalf of the neediest, most fragile and most disabled members of our society, including your family members and friends. Our work is increasingly costly and your contributions are tax deductible. Please be as generous as you are able. *Happy Holidays to you and your loved ones. Best Wishes!!*

*More than 90% of VOR's support comes from families of people of mental retardation. Thank You!!*

### Coming Up

**June 9, 2007:** VOR Annual Meeting in Washington, D.C.

**June 10 and week of June 11, 2007:** VOR Washington Initiative Briefing and visits to Capitol Hill.



## Medicaid Commission releases report

After nearly 18 months and nine meetings, the Administration's Medicaid Commission tasked with recommending long-term solutions to Medicaid sustainability voted to pass a policy "road map" that drew scathing criticism from patient advocates. Critics charged that the commission failed to weigh-in on three of the most important issues that face the program: dual eligibles, mental health parity and the uninsured.

Gwen Gillenwater of the American Association of People with Disabilities, was the only Commission member to vote against the group's recommendations. "People with disabilities have not had good experience with managed care," Ms. Gillenwater said. "We need federal protections and safeguards."

The commission also called for eliminating an "institutional bias" toward care in nursing homes and other institutions as opposed to care in a "medical home." (See VOR's counterpoint, "Dispelling Medicaid Myths," on this page).

The Medicaid Commission's full report is available at: <http://www.aspe.hhs.gov/medicaid/nov06/Recommendations.pdf>.

(Sources: *Inside Health Policy* and *The New York Times*, Nov. 22, 2006). **V**

# The Administration's Medicaid Commission

VOR participated in five (5) Medicaid Commission meetings, providing testimony relating to the need for a full array of residential options, including facility-based care, community quality concerns, the potential of the Community Resource Center model, and the myth of an institutional bias. Special thanks to Irene Welch, Nancy Ward, Patricia Bennett, Mary Reese and Robin Sims for representing VOR at these meetings. Excerpts from Robin's testimony, which addresses the myth of an institutional bias, follow. For a full copy, please contact Tamie Hopp at 605-399-1624; [vor@compuserve.com](mailto:vor@compuserve.com); or visit <http://www.vor.net>.

## Dispelling Medicaid Myths - November 16, 2006 By Robin Sims, VOR First Vice President

I am the First Vice President of VOR. I also have 2 children with disabilities. Although their needs are very different, both are thriving in their own way. Heather is 23 years old and has a regressive form of autism. She has lived in an ICF/MR in Clinton, NJ – the Hunterdon Developmental Center – for the past 8 years. She needs constant supervision and assistance with all her self-care needs. She has violent outbursts and requires the expertise of a trained staff to keep her from hurting herself and others. Benny is now 20 years old and has Fragile X Syndrome. As he ages out of school services it is unknown what kind of work or programming will be appropriate for him. Many kids like Benny have no services after transition and the results have been from severe depression, regression and even death.

My focus today will be the myth of an institutional bias, with regard to Medicaid expenditures, **for persons with mental retardation** and developmental disabilities. The cause of this myth is the historical combining of figures for the nursing facility program with the ICF/MR program to comprise a total figure for "institutional spending." This co-mingling of people and services throws together people with MR/DD with the much larger physically-disabled demographic, including the elderly. Separating out ICF/MR funding from nursing home care "institutional" figures and comparing just the funding for people with MR/DD leads to dramatically different conclusions.

A) ICFs/MR comprise 20% of total Medicaid "institutional" spending. Nursing Facilities ("nursing homes") account for 80%.

B) Nationally, we spend almost 3 times as much on Medicaid home and community-based services than on MR/DD institutional services. Only 25.8% is spent on ICFs/MR; 74.2% goes to MR/DD community services.

C) From 1977 to 2004, overall fiscal commitment to community programs, as measured by the total amount spent from state and federal sources for MR/DD services per \$1,000 of citizens' personal income, increased by 486%. In contrast, institutional spending declined by 51%.

The myth that we spend more Medicaid money on ICFs/MR than on MR/DD community services can have dangerous consequences for our most fragile citizens. Federal and States have pursued initiatives to "rebalance" the system by increasing community supports at the expense of "institutional" (including ICF/MR) options. ICFs/MR may become uneconomical and extinct, risking the health, safety and very lives of people with severe and profound mental retardation.

The most fragile people of the MR/DD population are not going away. Their specialized care needs will continue to exist at the same or greater level into the future. Their care will continue to be expensive regardless of where they are being served; some studies suggest the cost of care could be higher in community settings for the most disabled and medically-fragile of our society. While there is an ongoing need to expand community-based options, it is short-sighted and morally indefensible to do so at the expense of an exceedingly fragile population. **V**

### Medicaid expenditures: 1995 – 2005

- ✓ Medicaid increased by 98.28%
- ✓ Community increased by 267.5%
- ✓ ICF/MR increased by only 25.9%

Remember - nursing facility care is mandatory but ICF/MR care and community care are both optional Medicaid services.



## Baucus Says Bush's Plan for Social Security Is 'Off the Table'

The incoming chairman of the Senate Finance Committee said yesterday that he wants to hold hearings on looming insolvencies in the Medicare and Social Security programs but that President Bush's plan to partially privatize Social Security is dead. "Don't waste our time," said Sen. Max Baucus (D-Mont.). "It's off the table."

Baucus said the rising cost of Medicare and other health costs is a priority for the committee, though he did not detail how it will approach those problems. He said he will hold "vigorous" hearings on the issue. The senator said he will propose legislation to simplify the Medicare prescription-drug program by streamlining the number of plans available and making it easier for people to choose one. (Source: *Washington Post*, Nov. 17, 2006). **V**

## Fed Reserve Chief Says Baby Boomers Will Strain U.S.

Unless Social Security and Medicare are revamped, the massive burden from 78 million retiring baby boomers will place major strains on the nation's budget and the economy, Federal Reserve Chairman Ben Bernanke said recently. Bernanke did not offer Congress and the Bush administration recommendations on how the massive entitlement programs should be changed. Efforts by the administration to overhaul the Social Security program - once a centerpiece of President Bush's second-term agenda - puttered last year, meeting resistance from Republicans and Democrats alike. (Source: *AP*, Oct. 4, 2006). **V**

## Legislative Update

### CMS Releases Long-Term Care Reform Plan

In May of 2005, CMS formed the Policy Council to help the Agency's senior leadership develop strategies to improve our nation's health care system. Long term-care reform was identified as a priority, to be guided by the following CMS principles:

- Increase consumer choice and control for older individuals, persons with disabilities and chronic illnesses of any age, their family members and caregivers; and ensure access to an appropriate array of institutional and home and community-based long-term supports;
- Reverse the institutional bias in long-term care services and increase flexibility for States; *[Editor's Note: See page 3, for VOR's rebuttal to the claim of an institutional bias for people with MR/DD]*
- Enhance quality measurement to enable the provision of high-quality long-term care in the setting most appropriate for an individual's needs, and improve quality and oversight in each setting and across settings;
- Reduce costs and promote payment mechanisms that support and reward better performance;
- Encourage personal planning for long-term support needs among individuals and their family members and caregivers, including greater use and awareness of private sources of funding;
- Support Administration efforts to pursue tax law changes for asset accumulation and long-term care tax clarifications to provide for private funding for long-term care needs;
- Improve coordination of long-term care and post-acute care services, as well as their related funding streams; and
- Utilize enhanced health information technology to better inform beneficiary choices, clinical decisions, payment, and care coordination functions.

CMS notes that its vision for the long-term care system of the 21st Century will:

- optimize choice and independence;
- be served by an adequate workforce;
- be transparent, encouraging personal responsibility;
- provide coordinated, high quality care;
- be financially sustainable; and
- utilize health information technology.

"Optimizing choice and independence means that beneficiaries will have greater flexibility to choose from a broad spectrum of long-term care services, including home and community-based and facility-based services," the report states.

The Policy Council also notes, "The Deficit Reduction Act (DRA) of 2005 was signed into law on February 8, 2006 and included many provisions that target long-term care reform and are consistent with the Agency's vision for long-term care. Implementation of the DRA provisions thus became a key element of the Agency's short- to medium-term strategy for reforming the long-term care system."

With regard to the "institutional bias," CMS indicated that "Medicaid ...still pays most readily for institution-based care as it has for the last half century." CMS also cited a need for the expansion of affordable and accessible housing. The CMS report is available at <http://www.cms.hhs.gov/MedicaidGenInfo/Downloads/LTCReformPlan2006.pdf>.



## VOR can help!

VOR can help by researching your newspaper's specifications for submitting Letters to the Editor and Op-Eds, and/or with the drafting of your message. Contact Tamie Hopp at 605-399-1624; [vor@compuserve.com](mailto:vor@compuserve.com).

# Reaching the Media: An effective grassroots advocacy tool

Letters to the editor and Opinion Editorials ("Op-Eds") can be powerful vehicles for influencing or inspiring public debate, making the case for your issue, or responding to recent issues and events. Reporters may call on opinion authors for interviews for future stories and elected officials read the opinion pages of their local paper to get an idea of what issues their constituents find important. The following editorials are good examples of how the media can be used effectively to make your advocacy point.

## Nebraska: Put heads together for best mental-health solutions

*(Author Mary Hepburn O'Shea is a licensed mental health practitioner and is provider of community homes for around 300 people in Lincoln with a variety of mental and developmental handicaps.)*

It is amazing to me that people are always touting community programs as an answer for everyone. The same claim is made in the mental health system — everyone should be in their own apartment in spite of the fact that those with serious mental and physical challenges are not safe in their own apartment.

You need different strokes for different folks, and each situation has to be evaluated individually. Also, consider the preferences of the people getting the services.

I have operated community programs for more than 40 years for people with various physical and mental challenges. I also have experienced having my profoundly retarded multiply handicapped daughter in a community program when we could no longer care for her at home. She had her hair pulled out by the roots, was bruised to the point she had to be taken to the hospital and could not walk without pain for a couple of weeks. She had to be taken to the emergency room frequently because of asthma attacks.

There were only three young ladies in the home, and they had 72 different people taking care of them in one year's time because they had difficulty keeping staff. It became painfully clear to me that my daughter's needs would be better met at Beatrice State Developmental Center (BSDC) because they had medical staff on grounds plus a small hospital. They had physicians, neurologists, dentists, and nurses who knew how to communicate with nonverbal clients, many who are in wheelchairs, have to be spoon fed and need consistent staff to know what is going on with them. At BSDC, she has beautiful grounds where she can walk with others and I don't fear she is going to break loose and get in front of cars in the community as she did for me.

The point is that for some people, the institution is the least restrictive environment. My daughter has more freedom at BSDC than she ever had in the community. I pick her up for a couple of hours every weekend. She is always clean, as are all the other people in her cottage of 16 people. If she has a bruise, they can tell me what happened. When she was

bruised in the community program, staff would not or could not tell me what happened.

Things will happen and do in both community and institutional programs, but there needs to be a continuum of service that includes some who live in their own homes or apartments, small group homes, larger group homes, intermediate and skilled care facilities and institutions. A college campus is an institution. Nursing homes are institutions in the community. Retirement centers and assisted living apartments are in fact institutions — where people live for services and friendships with people with similar needs.

There are ways we could use some of the BSDC services more effectively and include the community, such as a training center for teachers, nurses, physicians, etc., while they are in college and as a day center for people who do live in the community, and a vocational center. We have a beautiful large campus. Let's put it to good use and all work together.

Everyone is so busy trying to address the day-to-day stresses that we don't take the time to use our creativity constructively. Stop the nonsense and pull together. Great things can be accomplished that much better serve the needs of people if we evaluate what we have and realize there is not an infinite supply of money. We must look at people's needs and put our facilities to best use. BSDC is a part of the continuum needed. (Source: *Lincoln Journal Star*, Oct. 22, 2006). V

## Maryland: The wrong solution

*(Author Harry Yost, the father of a Rosewood resident, is treasurer of Rosewood Center Auxiliary and was appointed to the Rosewood Citizens Advisory Board by former Gov. Robert L. Ehrlich Jr.).*

If history is any guide, the state's intention with regard to the future of Maryland's four residential centers for people with mental retardation and developmental disabilities is crystal clear. Closed admissions, a steady stream of transfers, aging residents and understaffing have led to ever-decreasing populations at the residential centers. Even S. Anthony McCann, the secretary of the state's Department of Health and Mental Hygiene, said at a recent political forum that Maryland law and the Supreme Court's Olmstead decision



**Harry Yost's Op/Ed prompted several favorable Letters to the Editor – Here are a few examples (excerpts)**

"I hope and pray that, as (our new) governor, Mayor Martin O'Malley will do the right thing for our most innocent citizens by keeping facilities like the Rosewood Center open and well-funded. Our institutions should be built up, well-staffed and safe" (Amanda Erickson)

"As a 28-year state employee who has witnessed the transition from institutional to community-based care for the disabled, as well as the closure of a residential treatment center, I have seen firsthand the good and bad of both sides of this debate. Most people with developmental disabilities who have the functional skills to communicate their wants and needs even if they have a physical disability are best served in the community, if that is their choice. But for those individuals with more profound developmental disabilities which are often further compounded by medical issues. History has shown us that 'one size fits all' is a failed policy" (Janet Carbone).

"I think it needs to be said that the Rosewood Center's great strength is the training it provides to its residents, regardless of their disabilities. It takes special, dedicated people to train my daughter and the other profoundly retarded individuals residing at Rosewood" (Glenn Brown)

require closing of all such institutions.

On the legal side of this issue, however, families know better, and apparently so does Mr. McCann's boss. In September, then-Gov. Robert Ehrlich Jr. said that Olmstead "did not dictate the closing of institutions. ... For a relatively few, the institution may be the appropriate place and the least-restrictive setting." Families of residential center residents feel hopeful that the governor's remarks were sincere (they certainly were informed) and not campaign banter.

The issue of where to best provide residential supports for people with mental retardation and developmental disabilities is one of life or death for many residents. Experiences in other states that have embraced a "one size fits all" (community placement-only) philosophy to providing care should give Maryland policymakers pause. In 30 states and Washington, D.C. - and in federal reviews - there have been reports of abuse, neglect and death in community settings. *The Sun's* April investigative series on group home problems in Maryland followed reports dating back to at least 2001 by *The Sun* and other Maryland newspapers.

Ron Coleman, a former social worker and incident data analyst with the Maryland Developmental Disabilities Administration, who oversaw some community placements during the closure of Great Oaks in Silver Springs, has dire predictions if Maryland is intent on additional closures. Upon studying the state's internal data, he recently predicted, "If Rosewood is closed in the fashion of the Great Oaks experience, medically fragile residents, and those individuals

who are dangerous to themselves, will die in the community at a rate of 400 percent greater than if they stay at Rosewood; 13.5 percent will die within the first 18 month."

Behind the push for "community for all" is a coalition of advocates who support closure of institutions despite objections from families and regardless, it seems, of the end result. The community-only coalition has bought into the social policy of full inclusion (literally, in some cases, as some community-only advocates also provide community-based care and profit from the transfer of residents to their community homes).

Many families favor facility improvement, not closure. Recent state inspections at Rosewood revealed serious problems involving resident safety. Facility administrators and staff quickly addressed these problems to the satisfaction of state inspectors.

"Rosewood's mixed population, about 150 long-term residents who are developmentally disabled living with some 50 mentally incompetent defendants who have been committed to the center by the courts, is the heart of the problem," a state surveyor recently said. It should be obvious to anyone that serious problems will arise when residents who are dependent on their caregivers for every need are forced to live with individuals capable of armed robbery, assault or rape.

Maryland anticipated problems with mixed populations yet neglected to address them. Original plans were to limit court-ordered placements to a manageable 25 people; they now number 50 at Rosewood. Plans to move all such residents to Clifton T. Perkins Hospital Center in Jessup have been scrapped, with cost given as the reason. The state has also ignored Rosewood's anemic staffing levels, with current staff regularly clocking double shifts - a situation that contributed directly to the recent "immediate jeopardy" finding.

In addition to utilizing psychiatric hospitals, such as the Jessup facility, other states, including California and New York, have addressed the concern of mixed populations by serving court-ordered mentally disabled and developmentally disabled residents at specialized facilities dedicated to meeting their unique needs. Other states, such as Idaho and Tennessee, tackled the challenge by splitting their campuses in two, allowing for different licensed programs to accommodate two distinct populations, with dedicated staff, training, licensing and funding for each.

With documented tragedy, dire predictions and more than 13,000 Marylanders needing services, citizens ought to be crying foul. Families of people living in residential centers and those who have been forcibly moved are crying, but we haven't stopped fighting. Maryland's most vulnerable citizens with mental retardation and developmental disabilities deserve safe and adequate services. For now, for most of these vulnerable people, those services are best delivered in Maryland's four residential centers. (Source: Harry Yost, *The Baltimore Sun*, Nov. 6, 2006). **V**



## California: The questionable use of quotas

(Author Mary McTernan, Ph.D, is VOR's President)

VOR, a national organization speaking up for people with mental retardation and their families, finds California's use of quotas to direct where individuals must receive residential services inhumane ("Lawmaker claims quotas for moving disabled exist," *The Oakland Tribune*, October 26, 2006).

Contracting for transfers in exchange for financial incentives is akin to car salesmen selling vehicles, or retail workers moving a pre-determined level of merchandise. People are not shoes, shirts, appetizers or cars to be sold; treating them as such is unconscionable, and, as Assemblywoman Noreen Evans notes, illegal.

In one case, the North Bay Regional Center has spent over \$100,000 in public funds in litigation to force the community-placement of just one Sonoma Developmental Center resident. It seems clear that this Regional Center is motivated not by the needs of people with mental retardation, but by financial incentives and quotas.

VOR applauds Assemblywoman Evan's efforts. Community placement is a laudable goal when it is the preference of the resident and his/her family. Nothing in the State's quota system speaks to person-centered needs or choice, as required by federal law. As stated so well by Assemblywoman Evans, the system puts a bounty on the heads of California's most disabled, most vulnerable, neediest citizens with profound mental retardation. This practice screams out for compassion and reform. (Source: Submitted to the *Oakland Tribune*, Oct. 26, 2006). **V**

## Massachusetts: Caregivers pay the price

(Author Eileen McNamara is a Columnist for the *Boston Globe*)

Neville Pottinger is accustomed to elected officials playing politics with his paycheck, but he will never understand why the first workers targeted in budget battles on Beacon Hill so often are the ones with incomes so low that many qualify for food stamps.

Pottinger is 61, a 23-year employee of a nonprofit agency under contract with the state to provide vocational, residential, and support services to individuals with mental retardation. He makes \$28,000 a year. Governor Mitt Romney just revoked the less than \$10-a-week pay raise that the Massachusetts Legislature promised Pottinger and more than 30,000 other direct-care workers last summer.

"I was expecting it," Pottinger said with some resignation about the elusive pay increase. The raise, retroactive to July 1 when the state's fiscal year began, was to have been reflected in a big check delivered the first week in December. "It would help with the electricity bill and the gas

prices," Pottinger said. "It is very strange to me. If government is supposed to help people, why would he choose to cut those of us whose job it is to help people?"

Why indeed?

Romney would have us believe that it was not his presidential aspirations but a looming fiscal crisis that forced him to use his emergency powers to hack \$425 million from the state's \$25.7 billion budget. But even the ever-cautious Massachusetts Taxpayers Foundation has said that tax revenues are coming in at such an encouraging rate that the cuts might well prove unnecessary, especially so early in the fiscal year.

If Romney wants to establish his credentials as a tough fiscal manager, why rescind \$28 million earmarked for pay increases for those who take care of the blind and the disabled, who work in juvenile detention facilities, or who work with adults with mental retardation? No one is getting rich giving sponge baths to the disabled. Everyone who anticipated these miniscule pay raises makes less than \$40,000 a year; most make less than \$25,000. If there is fat in the state budget, it is not in this line item.

Pottinger could make more money somewhere else, but he drives between his home in Medford and his job in Reading every day to help men and women perform the simple tasks that yield them a small financial stipend and a large dose of self-esteem. He has known some of his clients so long he could not imagine seeking other, better-paying employment.

"We keep afloat," he said of himself and his wife, a low-wage hospital worker, with whom he has raised six children. All of them "are doing better than we are," he said with a laugh that was both bemused and grateful.

Pottinger's long tenure in human services is the exception in Massachusetts, according to Tina Claydon, the residential director for ARC of East Middlesex, the nonprofit charitable corporation that pays Pottinger under its contract with the state Department of Mental Retardation. "Our turnover is very high. We have to recruit people from overseas because the wages are below the level most people here will accept."

It is not unprecedented, Claydon said, for a high-functioning client living in a group home to earn more money at a job than the direct-care worker providing residential support. "Is it any wonder we can't keep workers?" she asked.

In a letter to Senate President Robert E. Travaglio and House Speaker Salvatore F. DiMasi this week, Grace Healey, executive director of the Association of Developmental Disabilities Providers, compared Romney to the Grinch who stole Christmas. "Workers knew that they would soon receive a significant check that would help them through the holidays, which makes this action even more hurtful," she wrote.

There are those on Beacon Hill who argue there is plenty of time in January for lawmakers to restore the cuts. Why rush back into formal session before the holidays to undo the damage that most lawmakers agree these cuts will cause?

Why? Neville Pottinger is why. (Source: *The Boston Globe*, Nov 15, 2006). **V**



# State News

## Wisconsin: Disabled residents, families confront care dilemma

In 1963, the President's Panel on Mental Retardation declared residential institutions for the disabled "a disgrace to the nation." Since then, a series of legal rulings and congressional acts has gradually rerouted people with mental retardation, epilepsy, autism, cerebral palsy and other developmental disorders from institutions to adult day care centers, sheltered workshops and group homes.

Advocates for the developmentally disabled assumed that the savings would follow people from institutions back to their communities to provide for their care. "Instead, they went into general revenues in most cases," said Beth Swedeen, program coordinator for the Waisman Center in Madison, which studies issues related to human development and disabilities.

As a result, Swedeen said, families increasingly took on the financial and time commitments.

So, Wisconsin counties cobble together a combination of local and state tax dollars to "pull down" federal Medicaid waiver money. When the state and local money runs out, counties start waiting lists. Statewide, about 5,000 developmentally disabled people are on waiting lists, and almost every county has one. Some people have been waiting for 10 years. The real problem begins when an individual turns 21.

Disabled kids lose what they don't use, Swedeen said, and teachers find it demoralizing to teach skills when they know that many students are "graduating to nothing."

Also a concern are those individuals who have not sought needed services. It's a ticking time bomb, said Steve Stanek, planning

director for the Wisconsin Council on Developmental Disabilities. "They will need housing or someone to take care of them, transportation, case management. Those are dollars that have not been planned for in the county budget," Stanek said.

Outagamie County Supv. Chuck Schmidt said his heart goes out to families with disabled children. But while he believes that government should take care of people who don't have loved ones to help them, he doesn't think it's government's place to intervene as long as parents are still able to care for their

disabled children.

"I have people in my district who have problems, too, and they're worried about being taxed out of their

homes. How do I justify

taking their money and giving it to other families for non-emergency situations? We're not God. We can't fix everybody's problems."

Parents, however, are not legally responsible for their children, including disabled children, after they turn 18. Nor are siblings. If a family is unable or unwilling to take care of an adult who can't function independently, Wisconsin courts usually order counties to assume the responsibility. (Source: *Post-Crescent*, Nov. 18, 2006). **V**

## Toronto: Nobody 'pushed out,' minister promises

Madeleine Meilleur, Ontario's minister responsible for community

and social services said the 2009 closing date for the last three institutions for the developmentally disabled is set in concrete.

Toronto's three institutions, have about 1,000 residents. In 1975 there were 16 centres throughout the province with more than 7,000 residents.

Meilleur promises that all of the money saved from the closings will follow the residents out into the community and says that she has received many thanks from families who were initially wary of the move. The ministry has also provided an extra \$274 million to support those already in the community.

However, she admits the process has not always worked out perfectly and there have been botched placements.

"For all of these sad stories there are hundreds of very good stories," she says, adding the process

involves a great deal of diligence.

When asked about the benefits of being moved out of a developmental centre and into a nursing home as is the case for at least three people, Meilleur replied, "They have the same rights to go to a nursing home as any Ontario resident." This was also her reply to the high rates of hospitalization of the developmentally disabled in the community.

Four networks of special care are being established throughout the province to help professionals meet the heightened needs of the developmentally disabled, she says, adding that no one will be discharged without having a family doctor arranged to look after them.

This is not an eviction but a carefully planned process, she says.

*"Well-meaning reformers who tell us how terrible institutions are should be wary lest they become unwilling accomplices to politicians who only want to walk a tight fiscal line . . . No politician is going to say he is against caring for the handicapped, but he can talk in sanctimonious terms about efforts to preserve the family unit, about families remaining independent and self-sufficient. Translated, this means, 'You got your troubles, I got mine.'" ~ Fern Kupfer (Newsweek, 1997)*

*"[Savings] went into general revenues in most cases. As that happened, community programs were then never funded to expand and support people with disabilities in their communities."*  
~ Beth Swedeen, Waisman Center.



Soon, community living will be the only option in Ontario for those born with developmental disabilities, no matter how fragile their health. They will either stay at home with their families or move into the group home system when they are older.

Doug Elliott, the lawyer who represented the parents in their battle to keep the centres open, says de-institutionalization doesn't have a good history in Ontario.

"We were skeptical. We've seen what happened to people with the closure of psychiatric hospitals. They closed the facilities and solved the

*"You have two powerful voices. The community living movement, which will brook no exceptions no matter how profound the need and the desire of government to go out of the direct service delivery . . . The closings are the result of the lobby group and the government having common goal" ~ Doug Elliot, attorney for the families in Toronto.*

problems later. That's inappropriate. The families are an after-thought." At a minimum, the government should "grandfather the people who are there and want to stay in them and slowly wind them (institutions) down," says Elliott, whose specialty is cases against governments.

At its core is the community

living movement's strong belief that "institutions are inherently evil," he says. It is a philosophical belief and they are "true believers," says Elliott. This allows them to override the objections of the residents' families.

Once people leave these institutions, they become the responsibility of the agency running the group home, not the government. The Ontario government is only following discharged patients for three months and no tracking system is in place to report on the success or failure of placements (Source: *Toronto Star*, Nov. 17, 2006). **V**

## Texas Comptroller calls for end of call center contract

Texas Comptroller Carole Keeton Strayhorn today recommended the state immediately terminate its contract with Accenture, the private company which was hired by the Governor's administration to administer health and human services to needy Texans.

After her five-month review of the Accenture contract she uncovered wasteful spending and poor contract management by the Health and Human Services Commission.

Strayhorn's report found that since Accenture began operations on December 1, 2005, CHIP enrollment has plunged by 8.5 percent, 27,567 children through August 2006. Enrollment in children's Medicaid also fell during this time by 2.9 percent, 53,937 children. Children who were inaccurately denied benefits were in fact eligible.

"In addition," Strayhorn said, "I found that rather than saving money in this biennium, this contract will cost the state almost \$100 million more than budgeted while fewer children and families receive the needed benefits." (Source: *Strayhorn Press Release*, Oct. 25, 2006). **V**

## Missouri: Panel wants more oversight of state-run homes

A state government task force has released a draft report of 20 ways to better protect Missouri's mentally disabled residents in state and private homes and immediately ordered internal investigations. Among the task force recommendations:

- Tougher criminal penalties for abusers
- Fewer, but more focused, internal reviews
- Outside reviews of state-run centers
- Fines for poorly run private facilities
- More training and pay for caregivers
- A toll free number to report abuse
- Public access to completed investigations.

## Also from Texas:

### Despite problems, State continues push to privatize

The state has been trying to modernize the state's public benefit system for more than a decade, moving away from client-based offices to call centers that handle cases on an assembly-line basis. In 2005, the state awarded a five-year, \$899 million contract to Accenture LLP to operate call centers. The privately administered system has been plagued by problems: technical difficulties, staffing shortages and inadequately trained personnel. Despite these and other problems uncovered by the Texas Comptroller, Texas seems poised to enter into a deal that would privatize the computer-technology departments of 27 state agencies. (Sources: *San Antonio Express-News* and *American-Statesman*, Nov. 20, 2006).

The report will go to Gov. Matt Blunt, who formed the task force in June in response to a St. Louis Post-Dispatch investigation that found failures in a system that was supposed to ensure proper investigations of suspected mistreatment of the 11,000 mentally retarded and mentally ill residents in full-time care overseen by the state. The investigation revealed 21 deaths, 323 injuries and almost 2,000 other incidents tied to abuse or neglect by caregivers from 2000 through 2005. State auditors have found that the state hasn't properly logged abuse in private group homes.

The fate of Bellefontaine Habilitation Center in north St. Louis County remains unknown. Blunt has said he plans to close it, but he later said he would reconsider it if the task force said so. The draft report does say the state should keep open centers for mentally retarded residents so long as there's a need for them, and that the state should pursue outside accreditation for such centers. (Source: *Associated Press*, October 26, 2006). **V**



## **Oklahoma: County Judge calls for guardianship law reform**

Tulsa County District Judge Linda Morrissey, one of two Tulsa judges handling most guardianships, said she has asked several lawmakers for new legislation requiring background checks for prospective guardians. Presently, no background checks on prospective guardians for adults are required by state law. A court study last year found less than half of guardians in Tulsa County filed their annual reports as required. (Source: *Tulsa World*, Nov. 12, 2006). **V**

## **Mass: Guardianship Rights Law**

In the mid-1980s, and with the support of state Rep. Marie J. Parente, Massachusetts families helped pass a "Guardian Rights" bill that requires the Mass. Department of Mental Retardation (DMR) to give guardians written, 45-day advance notice of proposed transfers of persons with mental retardation and gave guardians the right to object to inappropriate moves before an impartial hearing agency, the Division of Administrative Law Appeals (DALA). DMR cannot transfer any person while the appeal is pending. Moreover, DMR is prohibited from making emergency transfers of people with mental retardation in psychiatric hospitals. DMR actively opposed the legislation and has repeatedly tried to weaken it. The law is *Mass General Laws c. 123B, sec. 3*. (Source: *Newsline*, The Dever Association for the Retarded, Inc., Nov. 2006). **V**

## **Legal Briefs**

### **California: North Bay Regional Center challenges family placement choice in court**

The family of a Sonoma Developmental Center resident, Roy Whitley, was sued by North Bay Regional Center when Whitley's sister, Belle Maldonado, challenged the regional center's plan to move him out of Sonoma and into a community-care home. The suit is pending, although Terry Delgadillo, Secretary for the California Department of Developmental Disabilities (DDS), has indicated that mediation of Whitley's case may be pursued. To date, the North Bay Regional Center has spent more than \$100,000 on its legal efforts to transfer Mr. Whitley from Sonoma Developmental Center. **V**

### **Tennessee: Greene Valley Developmental Center (GVDC) looking to the future after being dismissed from federal lawsuit**

A court order issued March 16, 2006, dismissed GVDC from a 1996 federal lawsuit by the U.S. Dept. of Justice, and advocacy organizations People First of Tennessee and the GVDC Parent/Guardian Association. Plaintiffs were seeking both to improve the level of care at the state's developmental centers and to offer residents of centers the opportunity to move into their respective communities. The State entered into a settlement agreement in 1997 and parties later petitioned the court for dismissal.

"Exiting the lawsuit allows us to really start to sculpt out our future," said Dr. Henry "Bud" Meece, GVDC's chief officer. That future will change GVDC's service from being just on campus to being a combination of campus-based service and community-based services.

Several GVDC residents will leave the campus and move into the community, Meece said. A condition of the court's dismissal is an agreement by the state to develop 16 four-person state-operated group homes in the geographic area served by GVDC, beginning in fiscal year 2007-08. The group homes

will be staffed by GVDC personnel, according to Meece. (Source: *The Greeneville Sun*, Nov. 15, 2006). **V**

### **Washington State: Parties come to agreement in waiver lawsuit**

A U.S. Magistrate judge preliminarily approved a settlement agreement October 3 for the *Boyle v. Arnold-Williams* lawsuit. Filed originally by Columbia Legal Services (2001) and joined later by Washington Protection and Advocacy (2005), plaintiffs alleged that Washington State did not advise individuals enrolled in its Medicaid home and community-based services waiver program about the availability for the range of services they could access through the waiver program. Plaintiffs also claimed that the State did not provide services in a timely manner, denied participants freedom of choice concerning providers, and denied due process when Medicaid services were reduced, terminated, or denied.

The settlement agreement requires the state to provide each HCBS waiver participant with an annual comprehensive needs assessment and written information regarding available waiver services. Each Individual Support Plan will detail all authorized services (incl. non-waiver services) necessary to meet the individual's needs. The state is also required to implement a "quality management process" ensuring all state and federal requirements are met, including due process and Medicaid freedom of choice.

A fairness hearing for the agreement will be held Dec. 15. (Source: *Community Services Reporter*, Nov. 2006. For subscription information, see <http://www.nasddds.org/Publications>). **V**

### **Texas: Waiting list lawsuit settled**

A settlement of the Texas waiting list lawsuit requires that the state aging and disability officials ask the legislature for more money to stop the growth of waiting lists. State Rep. Elliot Niashtat cautioned that the settlement might not mean the issue will be resolved because more money might not be available. **V**



**Forbes' 25 Most  
Generous  
Companies in  
2006**

- 1) Wal-Mart Foundation
- 2) Aventis Pharmaceuticals Health Care Foundation
- 3) Bank of America Charitable Foundation
- 4) JPMorgan Chase Foundation
- 5) Ford Motor Company Fund
- 6) Citigroup Foundation
- 7) Wells Fargo Foundation
- 8) Verizon Foundation
- 9) ExxonMobil Foundation
- 10) GE Foundation
- 11) SBC Foundation
- 12) Fannie Mae Foundation
- 13) Merck Company Foundation
- 14) Wachovia Foundation
- 15) MBNA Foundation
- 16) UPS Foundation
- 17) Intel Foundation
- 18) General Motors Foundation
- 19) Avon Foundation
- 20) BP Foundation
- 21) MetLife Foundation
- 22) Prudential Foundation
- 23) Pfizer Foundation
- 24) Procter & Gamble Fund
- 25) Eli Lilly and Co. Foundation



## **Donor's Forum**

**By Tony Padgett**  
**VOR Director of Resource Development**

### **Who do you know?**

I've listed on this page the nation's most generous companies, according to *Forbes Magazine* (July 2006). Knowing which companies are inclined to give to charitable organizations, however, does not mean instant financial success for VOR. The old adage of "it's who you know that counts" applies to charitable giving. Securing a financial contribution from a corporation is far more likely if the request is made or supported by an employee or retiree of the corporation, or by someone with some other connection to the grant manager(s). To support our request, VOR will develop a persuasive and professional proposal that meets all of the corporation's charitable giving guidelines; knowing someone within the corporation is critical to success. Through your connections you can arrange a face-to-face meeting to further explain the grant proposal and otherwise ensure that VOR's proposal is given fair consideration. Many companies have matching gift programs – they match your gift to VOR. [Note: Many companies also have matching gift programs for employees and retirees– the company will match your gift to VOR.]

Take a close look at this list and consider your other corporate contacts. If you have any connections to any of the companies listed, or other corporations or foundations, please contact me, Tony Padgett, at 847-253-6020; or [anthonypadgett@sbcglobal.net](mailto:anthonypadgett@sbcglobal.net). Thank you for your help.

### **News You Can Use: The Pension Protection Act of 2006**

I would like to bring to your attention new tax incentives for charitable giving that were signed into law on August 17, 2006. ***The Pension Protection Act of 2006*** includes a "Charitable IRA Rollover" provision that encourages individuals who are 70 ½ and older to utilize their support of their favorite charitable organizations like VOR. If this does not apply to you because of your age, it may benefit a family member. Under the new law, donors may now enjoy an exclusion from gross income for otherwise taxable IRA distribution up to \$100,000 per year (\$200,000 for a married couple) for the purpose of making a qualified charitable contribution.

The benefits of the Charitable IRA Rollover are:

- The charitable distribution counts toward minimum required distribution.
- The transfer generates neither taxable income nor a tax deduction, so even those who do not itemize their tax deduction receive the benefits.
- The transfer may be made in addition to any other charitable giving you have planned.
- You may transfer any amount up to \$100,000 per year directly from the IRA.

To be eligible for this benefit, gifts must meet all of the following criteria:

- The donor must be at least age 70 ½ by the date of the distribution to the charity.
- The gift must be made by December 31, 2007
- The gift must be made directly from the IRA administrator to the charity
- The recipient must be a qualified charitable organization (like VOR).
- The gift must not carry any benefits of value that would otherwise reduce the charitable deduction (quid pro quo benefits).

As you consider your philanthropy through the remainder of 2006 and 2007, be sure to consult your tax professionals to learn how these incentives may apply to your personal situation. If you have any questions, feel free to contact me, Tony Padgett, at 847-253-6020; or [anthonypadgett@sbcglobal.net](mailto:anthonypadgett@sbcglobal.net).

#### ***Important Note***

These may be the top 20 companies, but many other corporations also have charitable giving programs, including matching gift programs. Check with your employer – and ask your family members to do the same. And, let VOR know if we can help in any way. Sharing your corporate giving opportunities with VOR is an easy way to help. Tony Padgett 847-253-6020.



## Tribute Donations – New Opportunity!!

VOR now accepts Tribute contributions to dedicate an entire issue of *The Voice* to someone special. In exchange for your gift of \$1,000, VOR will dedicate one issue of *The Voice* to your special person and include a small (approx. ¼ page) article about that person in that same issue. For \$100, we will dedicate an issue of the VOR Weekly E-Mail Update to the person of your choice, and also include a short article. Traditional tribute gifts of any value continue to be welcomed, with individuals honored listed in the tribute section of the next issue of *The Voice*. Tribute gifts to VOR are a unique way to honor a couple's wedding, anniversary, birthday or other special occasion, or to honor the memory of a loved one. Thank you for your support! **V**

## Future Life and Estate Planning for Persons with Mental Retardation and Developmental Disabilities

Timely consideration of estate planning issues is critical, especially if you have a loved one with special needs who relies on government programs and support. Failure to plan appropriately could jeopardize your loved one's placement. There are estate planning strategies that can assure that basic needs are covered without jeopardizing Medicaid eligibility. Some estate planning vehicles, including special needs trusts and wills, also provide a unique opportunity to designate charitable beneficiaries, like VOR, as part of the overall security you seek. VOR has developed an informational resource on estate planning issues. Contact the VOR office for a free copy of "Future Life and Estate Planning for Persons with Mental Retardation and Developmental Disabilities, or access a copy online at <http://vor.net/guardianship.htm>. **V**

## Taking Stock: VOR accepts gifts of appreciated securities

Many people use stocks as a way of making gifts to their favorite charitable organization. Stocks that have appreciated in value allow the donor to potentially make a gift much larger than what was originally planned and the donor benefits from a "Double Tax Break." By making a gift of stock(s) to a charitable organization, you avoid any capital gains tax while also deducting the full value of the stock as a charitable deduction. Consider a gift of stock to VOR today!

**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

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☐ 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: \_\_\_\_\_

## About VOR

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

Send articles to be considered for use in *The Voice*, or other VOR publications, to VOR, 5005 Newport Dr., Suite 108, Rolling Meadows, IL 60008; 847-253-6054 fax; [vor@compuserve.com](mailto:vor@compuserve.com) (attn: Tamie Hopp).

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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.

Dec06



## VOR Welcomes Tribute Donations

Gifts have been received

### In Memory of

Richard Allen  
Bert Barnett  
William Burke  
Dickie Gayheart  
Marty, Ellen and Nancy Pratt  
Mary Jo Schutter  
Esther Sydney

### In Honor of

Jeb Bingham  
Jeffrey Gans  
Heather Sims

### In Celebration of

The Marriage of Eugene and Sasha Jarvis

## VOR Tribute Donations

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Other Occasion \_\_\_\_\_ Birthday \_\_\_\_\_

Amount \_\_\_\_\_

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

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

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