VOR
the Voice
news and Views of VOR supporters

Winter 2010

AS WE GIVE THANKS AND CELEBRATE OUR MANY BLESSINGS THIS YEAR, PLEASE PUT A "GIFT" TO VOR ON YOUR HOLIDAY GIVING LIST!

WONDERING HOW TO GIVE AND WHAT YOU GET WHEN YOU MAKE A DONATION TO VOR? THIS ISSUE IS PACKED WITH REASONS TO SUPPORT VOR!

Inside

VOR
Speaking Out for People with Mental Retardation

VOR-A nonprofit association speaking out for people with mental retardation and developmental disabilities

President's Message

Presidential Happenings

By Robin Sims, President

It has been a busy year! From New Jersey to Arkansas to Washington, D.C., I've been busy advocating for my own children while also working for all of you as VOR's President.

In this column, I'll share some of what I've been up to. My activities span from the task of considering where to hold our convention in 2012, to my work as an expert on behalf of the State of Arkansas, and as an invited participant at the National Summit on Disability Policy, July 2010.

Arkansas Bound!

In March, I had the pleasure of touring the Conway Human Development Center in Arkansas. I was asked by the State of Arkansas to serve as an expert in its defense of the Center. The U.S. Department of Justice (DOJ) filed a lawsuit alleging that Conway residents were not being served in the least restrictive environment appropriate to their needs. I observed otherwise. In fact, my observations regarding the care received by Conway residents exceeded my expectations. The trial has concluded. Rarely does a state take on DOJ. Settlement is the more typical outcome (for example, see the Georgia article on p. 8). Thus, the whole nation awaits the judge's decision in Arkansas, expected sometime next year.

The National Summit on Disability Policy

In July, I represented VOR at the National Council on Disability's (NCD) annual Summit on Disability Policy. The theme for this year's event was "Living, Learning and Earning." When I first arrived, I was not sure how VOR's issues could become part of the dialogue. The participants that I encountered did not have any cognitive disabilities. Still, I recognized that my purpose was to use every opportunity to teach others about who our loved ones are and why their voice is different but no less important.

I took my teaching purpose seriously. Tom Perez (DOJ) was one of the first speakers. Mr. Perez addressed, as expected, the DOJ agenda to use *Olmstead* to move people out of ICFs/MR and other "institutions." With pride he reported on the number of briefs filed. With disappointment, he reported that some cases did not go his way. When he left the room, I saw my teaching moment. I caught up with him and interrupted someone from Pennsylvania who was urging DOJ to "get involved with closures" in her state. I re-introduced myself (we had met before) and commented that his remarks about centers and DOJ's attacks on them made it seem like some sort of game. I reminded him that families are not happy about having DOJ telling them that they do not have the right to choose an ICF/MR, and that many people who have been displaced from ICFs/MR have been harmed or have died. Mr. Perez quickly tried to soften his remarks, but it was too late. Along with a room full of people, I heard his words. Hopefully, our conversation will affect his speeches going forward.

Similar comments were made by Kareem Dale, an advisor to the Presi-

See Happenings continued on page 10

Robin Sims

I've given, have you?

When we say "Every Member" we mean it, including me. The Every Member Campaign asks that every member pledge a small amount to donate each month for one year. My family and I are participating, and so are VOR Board Members and staff. The idea is that with each of us giving a little each month, together we are contributing a lot to the advocacy success of VOR. See page 10 for details. Thank you!

In this issue

VOR MISSION STATEMENT

The mission of VOR is to unite in advocacy, educate and assist families, organizations, public officials, and individuals concerned with the quality of life and choice for persons with mental retardation within residential options including home, community-based options and facility-based care.

Membership, giving keys to VOR's continued success

Julie M. Huso

Fall is in the air and that means many family days and other celebrations at facilities around the country.

By Julie Huso
Executive Director

I've been fortunate to have had the recent opportunity to participate in several celebrations around the country on behalf of VOR.

In September, I had the pleasure speaking to families at Shapiro Developmental Center in Illinois. I was warmly welcomed and enjoyed meeting new people and visiting with longtime VOR friends. While in the Chicago area, I also attended the 30th Annual Misericordia Family Festival.

In October, at the invitation of VOR Second Vice President Ann Knighton, I traveled to Augusta, Georgia, to attend and present at the Annual Family Day at Gracewood ICF/MR. I was also joined by VOR member Irene Welch who resides in Florida but has had significant advocacy involvement in Georgia and Florida. For the third year, VOR was given an opportunity to discuss our many activities and achievements, and the importance of supporting VOR by joining as members.

Left to right: Ann Knighton, Najhee Jackson (from Congressman John Barrow's office); and Julie Huso

Irene Welch

Terry Kopansky

VOR was also invited to be the guest speaker at Murci-Homes 50th Anniversary celebration in Nashville, Tennessee. I was honored to speak about "The National Perspective: Challenges Facing Mur-Ci Homes and ICF's Today" with a group of approximately 150 individuals. I shared the VOR mission and had an opportunity to visit with several longtime VOR members. Congratulations to Murci-Homes and a big thank you to Terry Kopansky, the executive director at Murci-Homes for being a wonderful host.

AHCA (American Health Care Association), a longtime advocacy partner to VOR held its annual conference in October with over 2,500 people attending throughout the United States. VOR was invited to speak as part of the "Developmental Disabilities" track. The title of my presentation was "Provider (Grassroots) Advocacy: Taking Care to a New Level." AHCA's senior director of government relations said, "it was one of the best grassroots advocacy presentations she had seen." It was indeed a pleasure to be a part of this wonderful conference.

See **Membership** continued on page 4

VOR

Rosa's Law Changes 'Mental Retardation' to 'Intellectual Disability'

S. 2781, "Rosa's Law," which will change references to "mental retardation" in certain federal laws to "intellectual disability" has passed. Prior to its passage, VOR and the American Health Care Association (AHCA), sought stronger assurances that the terminology change would not affect state or federal eligibility for benefits. The Senate sponsor of Rosa's Law agreed and the law's Rule of Construction was strengthened to better ensure continued eligibility now and in the future.

Continuing Resolution passes; Congress adjourns

Just prior to the start of the Fiscal Year 2011 (Oct. 1), Congress passed a Continuing Resolution which funds the federal government, at FY 2010 levels, until December 3rd. After passing the continuing resolution, Congress adjourned until after the fall elections. Congress is scheduled to return for a lame-duck session starting on November 15th. Congress will need to move the appropriations bills to fund the federal government for the duration of the federal fiscal year, or pass another Continuing Resolution. The new 112th Congress will begin its first session in January.

Membership continued from page 3

In November, I will have the privilege of being hosted by VOR Board Member, Sandra Reeves, in Texas

Sandra Reeves, VOR Board Member

and will have the opportunity to visit several facilities and present at the Richmond State Supported Living Center (SSLC) Family Association meeting.

VOR needs your continued support!

All these opportunities to meet people face-to-face and share information about VOR's Mission and activities are effective and worthwhile ways to spread the VOR message. VOR's vision is to advocate for choice and a full continuum of care for a full continuum of individuals. Whether that is in their own home, a community home, or in a facility setting.

At every opportunity, I encourage families and others to support VOR with a membership. Numbers count when it comes to grassroots advocacy. We need renewing memberships and new members to have a greater and ever expanding number of individuals speaking out on behalf of your loved ones.

In addition to joining, there are other ways to also make a financial commitment to VOR:

- **The Every Member Campaign**: Details can be found on page 10.
- **Year End Donations** are needed to maintain our current and increasing requests and services.
- **Memorials and Honor Gifts:** In lieu of flowers a memorial gift can be made to VOR. We acknowledge all donations to family members and also in *The Voice*.

  Honor a family member or friend when they are celebrating a birthday, anniversary or maybe when someone does something nice for you — thank them with a VOR membership.
- **Remember to include VOR in your future planning** by providing a bequest in your will documents.

During turbulent economic/financial times all of us must take a second look at what we really need in our daily lives. ***You need VOR and VOR needs your continued support!!*** We are making a difference and protecting your loved ones right to CHOICE!!

Please take a moment to make a financial donation to VOR in whatever capacity you can. Your gifts are greatly appreciated.

Thank you!

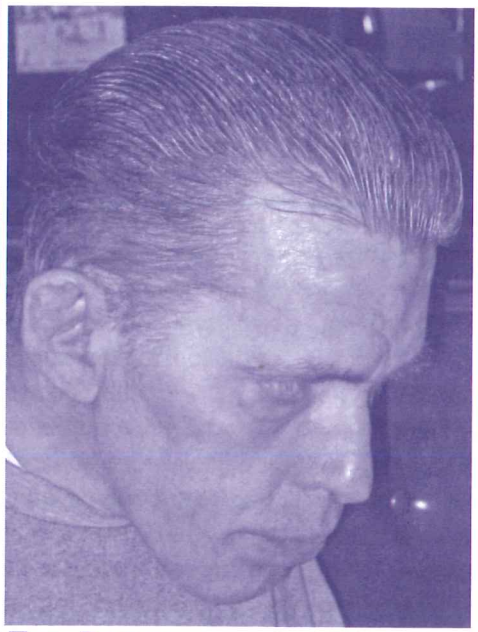
Special Offer from EP Magazine

Through December 31, *EP (Exceptional Parent) Magazine* is offering VOR members a FREE one-year subscription to *EP Digital*. Current members can get their subscription started immediately by emailing jmcginnis@eparent.com. Let him know you are a VOR member and provide your name and e-mail address. Learn more at VOR's website (www.vor.net , click "Join").

A Sibling's Perspective

By Hugo Dwyer, VOR New York State Coordinator

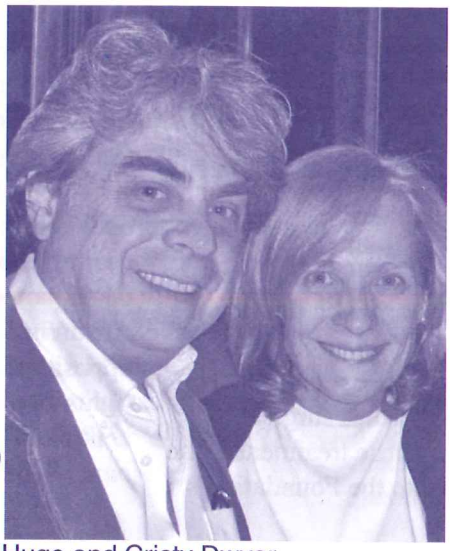
My brother, Tom Dwyer, turns 54 years old this November. He is has profound intellectual disabilities, is autistic, and bi-polar. He has physical problems, including early stages of Parkinson's disease and a loss of vision through a detached retina and cataracts. Tom tends to swallow his food without chewing, so all of his food must be ground or pureed so he won't choke on it. He doesn't speak, and cannot brush his teeth or go to the toilet by himself. Tom requires one-on-one care 24/7.



Tom Dwyer

When he was four years old, my parents determined that they were unable to provide the level of attention he needed at home. They enrolled him in a series of schools and facilities over the years, trying to find services that were appropriate to his needs as his body developed though childhood and adolescence and into adulthood. For the last thirty eight years he has been at Southbury Training School in Connecticut.

Throughout most of my life, Tom was not very high on my radar. My parents had taken responsibility for his care, in participation with the State of Connecticut, Southbury Training School, and other groups and facilities. Often, when asked if I had any brothers or sisters, I would just say that I had an older sister. It was far easier than going into an explanation of Tom and his condition, and people often don't want to hear all of that anyway when they ask about your siblings. In addition, there was the social stigma attached to people with intellectual disabilities, and I, like most young people, didn't want anything to do with social stigmas, even if they were my brother's and not mine. It was easier to detach and minimalize my involvement with his care.



Hugo and Cristy Dwyer,
VOR New York State Coordinators

Years passed. My father died, my mother became sole guardian. As she aged, my sister willingly took over guardianship. That was fine with me. I still visited Tom a few times a year, but kept my involvement in his life and well-being to a minimum. My mother passed on a few years ago, leaving my sister Marty the sole guardian. She does well, is involved in Tom's care as well as in keeping Southbury from closing due to the legal wranglings of the State of Connecticut and the local Arc's. But it has become clear to me that I had better get involved, too. If anything should happen to her, I would be the only there for Tom. I knew I had better get caught up in understanding what his needs were, how they were being met, and how and when family members needed to make choices in the many decisions involving his care.

I am now applying for co-guardianship for Tom, and have started paying more attention to him and his needs. I have also become more involved in the politics of disability issues, and have joined VOR as a way of learning more about the intricacies of the service system and as a way of contributing to better solutions for people like Tom.

My situation is not unique. There is an obvious need for siblings to participate in the care of people with mental retardation yet many of us find it difficult to step up to the plate. In many families, however, the care of the one child is unequally distributed among the siblings, with one or two family members bearing all of the responsibility. I hope that by talking about this openly, I can encourage others to take a more active role in the care of their brother, or sister, or other relation. I honestly believe that Tom has benefited greatly from my parents' and my sister's involvement in his care. His health and happiness have improved greatly over the years. From all I have witnessed, I know that family participation also helps the staff and caregivers who work with our loved ones on a daily basis.

I still consider myself a novice at this, even though I am four years older than Tom and have had an awareness of his situation all of my life. I feel I have so much catching up to do and so much to learn to get good at this, because my

See **Sibling** continued on page 11

VOR

Guardianship — who needs it and why? Protecting the rights of your love

Family Association offers services

CCMR, Inc. an advocacy organization in Massachusetts (www.ccmradvocates.org) has begun offering guardianship services to individuals who are in need of assistance with navigating the guardianship process for individuals with intellectual and developmental disabilities (ID/DD).

"This is something the board has wanted to do for quite some time," said David Hart, CCMR Board President. "With the changes in guardianship in Massachusetts we waited for the opinion of our legal counsel as to whether this would be a viable option for CCMR and the implications of a non-profit advocacy group serving as guardian or co-guardian of individuals with ID/DD."

On a personal level, Hart, along with his father Charles, have on several occasions over the last 15 years volunteered to serve as guardians of individuals with ID/DD. However, neither received "a single call" from the now-named Department of Development Services (DDS), says Hart.

Yet the need for guardians in Massachusetts for people with ID/DD remains high. Over the years CCMR has fielded complaints from family and guardians about lack of access, information, and services. Complaints also included being left out of the process, not being adequately notified about annual "ISP" meetings and transfers from current living arrangements without family input. Also, as current guardians age, they seek replacement or successor guardians.

This need for guardians, and an apparent (alarming) shift in DDS attitude, is what ultimately prompted CCMR to act.

Despite the obvious need, Hart learned recently from a senior DDS official that DDS personnel are now telling parents and others that "guardianship by a family member or someone close to the individual is not needed and in fact a detriment to the individual with ID/DD [because] people close to or family cannot make the difficult decisions that need to be made because of emotional ties." The official also stated that "family should stay out of the way and allow the professionals to do their jobs."

This stance, coupled with very public failings by corporate guardians, prompted CCMR to step up, beginning with a feasibility study on offering guardianship services.

"The situation involving Anna, plus the state's attitude about family guardianships, were really the rallying call CCMR needed."

Anna Tross was a resident of the Fernald Developmental Center, an ICF/MR in Waltham, MA for most of her life. Her corporate guardian was the Greater Boston ARC. Her original guardian, who felt Anna was being provided good care at Fernald, was fired for insubordination. Her replacement, another employee at Greater Boston ARC, caused Anna's transfer to a group home, where she died approximately six months later. During this six months, her family, friends and former Fernald staff were denied access to visit her.

The guardianship services CCMR will offer will include attending all pre-ISP and ISP meetings, medication review meetings, review of current family status, and to best of CCMR's ability "the wishes of the family" will be met.

"The guardian is a key part of the individual with ID/DD's team and there should be complete transparency," says Hart. "When dealing with the current corporate guardianship model that transparency is not as clear as it should be and in many cases the ones closest to the person with ID/DD (usually family) is left out." (Source: CCMR, October 2010)

The Southbury Training School (STS) Foundation's Guardianship Program

The STS Foundation was established in 1964 to promote the welfare of residents of STS, a state-operated ICFs/MR in Connecticut. In addition to supplementing the services provided by STS, beginning in 1981, the Foundation also started its Guardianship Program, which now provides guardianship services to about 170 residents of STS, and another 60 former STS resident who have moved into community residences.

The Guardianship Program, which is supported solely by private donations, is supervised by a registered nurse who has extensive experience with intellectually disabled individuals. She is assisted by two additional employees and one member of the Foundation's Board, who has worked full time for many years as a volunteer. In consultation with the Board's Guardianship Committee, which is chaired by a volunteer physician, the registered nurse monitors decisions regarding medications as well as surgical, dental, psychological and psychiatric treatments. The services are provided at no cost to the Foundation's wards or their fami

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Nelson she heard "troubling" tes-
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The Importance of Guardianship — Your Questions Answered

Once a person turns 18, his/her parents are no longer considered the natural guardian. This is true even if the individual has a disability such as an intellectual disability. Parents no longer have the legal authority to make decisions for the adult with a disability unless they are appointed their child's guardian by a judge. This means that the law presumes that the person with a disability can make all of his/her own decisions.

What is Guardianship?

Guardianship is a legal process whereby someone is given the authority by the court to make decisions regarding major life decisions such as medical care, living arrangements, and sometimes financial management and act on behalf of a person who lacks the ability to comprehend and do those things for him/herself. The process is designed to protect an individual who cannot make decisions for himself/herself from being exploited, abused or neglected.

Do all persons need a guardian?

No. Just because a person is mentally or physically disabled does not mean that he/she must have a guardian. A good question to ask is -- can he/she manage his/her personal affairs by making decisions regarding money, understand and sign consents for medical treatment or medications, etc.

Who appoints Guardians?

Only a judge can appoint a guardian.

What does a Guardian do?

Guardians make significant decisions for the individual, called a "ward" by the court. The decisions could include medical consents and consents for medical procedures. The guardian provides necessary legal consent for psychotropic medications, special programs, athletic events (Special Olympics), participation in educational and financial decisions and access to confidential records and reports. The guardian also has authority to speak for their ward in selecting appropriate living arrangements. Essentially, the guardian does the same sorts of things that a parent does for a child.

A guardian is expected to visit and call to check on their ward and his/her care frequently. The guardian is required to renew their "Letters of Guardianship" annually, by turning in a report to the court describing how their ward did during the previous year.

Will I become responsible to cover all of my ward's cost of care if I become a guardian?

No, you are only responsible for making appropriate decisions for your ward as needed.

Are there different types of guardianships?

Yes. A "guardian of the person" gives the guardian authority to make decisions about the ward's personal affairs. If the ward owns property or inherits property or an estate, the ward would also need a "guardian of the estate." In most cases only a guardian of the person is needed.

Are there any things that a Guardian cannot do for his/her Ward?

Yes. The guardian cannot vote for the individual, cannot consent to sterilization, cannot voluntarily admit the ward for long term care nor interfere with marriage decisions.

How do I become the guardian of my family member with mental retardation?

You may work through an attorney and make a request in the form of a petition (application) for your appointment to an appropriate Judge. The petition or application must include documentation of a thorough examination performed by a physician or psychologist that explains why the individual in incapacitated. Also the application should be filed in the county of residence of the individual who needs the guardian.

How much will it cost?

The cost can vary by state and circumstances.

How can I pay for it?

If you do not have the money to pay the cost in full, ask the attorney if you can pay out the cost on a payment plan. Trust fund money can be used to defray the expense of seeking and maintaining guardianship. (**Source:** *Parent Association for the Retarded of Texas*).

VOR

Georgia: State and Justice Department reach settlement, deny choice

On October 19, in a legal settlement with the U.S. Department of Justice (DOJ), the Georgia Governor committed the State to spending millions to transfer more than 900 residents of Georgia's ICFs/MR to smaller settings by 2015. The settlement also requires the State to expand community-based services for 9,000 people with mental illness and to transition individuals with ID/DD currently in psychiatric (non-ICF/MR) settings to smaller settings.

To meet these requirements, the State will have to spend at least $15 million in 2011 and additional $62 million in the 2012 budget, or face stiff contempt fines. Some state officials have acknowledged that finding the additional money will present significant challenges.

Although DOJ has credited many advocacy "partners" in helping to reach this agreement, families and guardians of affected ICFs/MR residents were conspicuously absent from any negotiations and have registered their strong opposition to the elimination of ICF/MR care for their loved ones. VOR is working with families to explore legal options and to develop a strong coalition of others who share their concerns regarding the terms of the settlement.

Kentucky: The Council on DD seeks records in community death

The Council on DD, Inc. (NOT the state DD Council) has filed a complaint against the State for denying access to records for an individual with DD who died after being transitioned to a community placement from a state operated ICFs/MR. The Council alleges that it is entitled to receive these records per state law as a "social service agency . . . with a legitimate interest in the case."

Virginia: Arc/P&A lawsuit dismissed!

For unknown reasons, the Arc of Virginia voluntarily dismissed its lawsuit against the Southeast Virginia Training Center (SEVTC). Arc of Virginia was represented by the Virginia Office of Protection and Advocacy (VOPA). The Arc/VOPA lawsuit had challenged the State's plan to renovate and resize SEVTC.

A district judge had dismissed the case finding that the Arc had failed to establish a "case or controversy" ripe for judicial review. A federal appeal of the district court dismissal, filed by The Arc/VOPA, was pending. The voluntary dismissal of the lawsuit allows the district court decision to stand, in which the judge expressly recognized that personal choice was central to the U.S. Supreme Court's *Olmstead* decision. For background on The Arc of Virginia v. Kaine, visit www.vor.net/get-help/legal-resources/.

California Victory: State Supreme Court allows good decision to stand and remain published

Michael will be calling Sonoma Developmental Center home. A favorable ruling by the California Court of Appeals which found, in part, that Sonoma was the least restrictive environment for Michael, was allowed to stand and remain published, when on September 22, the California Supreme Court declined to review the case and rejected a "depublication" request. VOR, with CASHPCR, CAPT, and AMRA, filed a letter objecting to depublication requests.

Read the decision and VOR's letter objecting to depublication at www.vor.net/get-help/legal-resources/.

Thank you VOR for recognizing the importance of this case and for your efforts to save its precedential value. VOR's part was instrumental in the positive outcome!

~ Monica B. Wegner, attorney for Gail, Michael and James Bowen.

New Jersey: Judge allows P&A lawsuit to continue

A federal court judge has denied New Jersey's Motion to Dismiss, holding that a trial is needed to determine whether the state is justified in postponing a plan to move them out of the state-run developmental centers before 2015 because it can't afford to pay for it. According to her Sept. 24 decision, Judge Thompson said she could not decide the case without determining whether "New Jersey has an *Olmstead* plan that can be considered to be effectively working given the recent fiscal crisis and budget cuts." (Source: *NJ.com*, September, 2010).

Illinois: Olmstead victory for people with mental illness

A federal judge has given final approval to an historic agreement between the State of Illinois and a coalition of legal services organizations. The agreement in *Williams v. Quinn* sets forth a systemic process of giving approximately 4,300 persons with mental illnesses the choice to move out of large nursing homes known as "Institutions for Mentally Diseases" (IMDs) and into community-based settings.

The settlement calls for the transition of those class members who want to move and are able to move from IMDs to the community over the next five years.

(Source: *Access Living*, September 30, 2010)

VOR works for you!

"Without VOR's help, it is highly unlikely that a group of concerned family members and guardians would have been able to attain a team of attorneys who are seeking to intervene and be heard in a class action lawsuit, which threatens the right of people living in Pennsylvania's state centers to choose where they live." Bert Springstead, father/guardian to Craig, lead Intervenor in Benjamin v. Pennsylvania, a class action lawsuit filed by P&A. The families appeal regarding their request to intervene is pending before the 3rd Circuit Federal Court of Appeals.

Arkansas: Trial judge, attorneys tour Conway center

One month after the September start of the trial, a federal judge toured the Conway Human Development Center. Chief U.S. District Judge Leon Holmes visited the center Monday with attorneys for the U.S. Department of Justice (DOJ), who ege the state is violating residents' civil rights, and the Arkansas attorney general's office, which is staunchly defending the state against the allegations.

Holmes will use the information gleaned from his tour along with testimony taken over the course of about six weeks to determine whether, as DOJ claims, the residents aren't being cared for and educated in the least restrictive environment available. The state maintains that the residents are well-treated, in accordance with federal law. The trial concluded in mid-October. Parties are now preparing final written arguments.

Families across the state are strongly supportive of Conway. In August, more than 150 people gathered at the state Capitol to show their support, bringing with them a petition signed by 5,637 supporters of Conway and the other Arkansas centers. (Source: *Democrat-Gazette*, October 5, 2010)

Missouri: CMS denies waiver homes on campus

The Centers for Medicare and Medicaid Services (CMS) has denied Missouri's request to build Medicaid waiver (HCBS) group homes on the campus of a Nevada Habilitation Center, a Missouri-operated ICFs/MR. CMS noted that HCBS waiver homes are designed to be an alternative to ICF/MR services for non-residents of ICFs/MR. Building group homes on an ICF/MR campus, therefore, "does not comport with the requirements of the statute and regulation," CMS concluded.

The development of waiver homes Nevada's campus was a compromise offered by the state to allow residents to live in group homes on the center's campus. With the CMS denial, the state now plans to move Nevada's 64 residents into state-operated community-based homes over the next two or three years as the center is closed. Families have accused the Missouri DD Council of lobbying CMS to scuttle the state's plan to build waiver homes on the campus, a compromise families supported. The Missouri Planning Council supports the closure of Nevada.

New Jersey to create caregiver abuse registry

New Jersey has passed legislation creating an internal registry of caregivers who neglect or exploit developmentally disabled people under their care. The registry is intended to prevent abusers from finding new jobs caring for the disabled. When the Department of Human Services' internal investigations unit substantiates allegations of neglect or exploitation, the caregivers' name is forwarded to the department's commissioner for possible inclusion in the registry. (*NJ.com*, April 30, 2010)

California: Budget includes Lanterman closure plan

State legislators have passed a state budget package that includes language outlining the closure of Lanterman Developmental Center (LDC) in Pomona. Brad Whitehead, staff representative and advocate, noted that while the budget includes items called for by families and concerned staff to improve continuity of care, opposition remains to the closure of this vital and irreplaceable center. "Lanterman is so unique: We have everything our clients depend on all under one roof," said Whitehead, who has testified alongside family members at several legislative budget hearings. "Instead of closing their home, we should be looking at more ways to allow more Californians to truly benefit from all the professional services we offer." For more information about Lanterman, visit the Save Lanterman coalition's website at www.saveldc.org. (Source: *CAPT*, October 8, 2010).

Quality Matters: OIG's List of Excluded Individuals and Entities

The Office of the Inspector General (OIG) maintains a database which provides information to the health care industry, patients and the public regarding Excluded Individuals/Entities (LEIE) – those banned from participation in Medicare, Medicaid and all Federal health care programs due to an OIG exclusion action, such as a Medicaid/Medicare fraud or patient abuse. For example, if an ICF/MR (federally-licensed and Medicaid funded) provider employs or contracts with LEIE, the ICF/MR provider may face a civil monetary penalty by OIG.

VOR

VOR's "Every Member Campaign"! Together We *are* VOR.

What is the Every Member Campaign?

To meet current and expansion needs, we have established the "Every Member Campaign" with a goal of $48,000. This will provide the needed funding to meet our goals while continuing our current advocacy programs for every member.

VOR is over 3,200 members/households strong. It will only take $20 per month or a $240 donation for the year to meet this goal.

As one member stated:

"I think I can give up one gourmet coffee a week to make sure VOR is there to help my daughter when we need it."

Please participate!

As VOR members and contributors, each of you are part of a unique organization!

VOR is the only national advocacy agency that is unique in its fundamental mission to advocate in support of a full continuum of care options for people with intellectual/developmental disabilities, and their families.

Our success and effectiveness is undeniable.
The need for VOR is critical.
VOR is a good and necessary investment.
If not VOR, who?

VOR is only as strong as our members' support. VOR is supported 100% by membership dues and private donations. We receive absolutely no public funding.

We value and need your continued financial support. For VOR to continue our success and expand our advocacy, we have identified the following immediate advocacy needs:

- **An online "e-advocacy" program for immediate and easy responses to VOR's Action Alerts.**
- **A legislative advocacy workshop at VOR's Annual Conference and a related webinar for all.**
- **Expansion of VOR's State Coordinator Program so families can be prepared when they need to be.**
- **Contributions to the Burke Legal Advocacy Fund to expand our popular legal advocacy program.**

Thank You!

Please take a moment to complete the contribution form on page 11, which includes an opportunity to participate in the Every Member Campaign. Thank you. Your support will help us meet our goal for 2011 so we can continue to advance our efforts to be here when you need us to protect your loved ones!

President:
Robin Sims
Editor:
Rochelle Hagel

Happenings continued from page 2

dent, and others during the course of the two-day summit, but it seemed to me that the participant/advocates were really not interested in the issue. Their needs are not even remotely related to ours and they have no knowledge of our centers or the abilities of those who live in them. To me, that makes the ideology of Perez, Dale, and others all the more dangerous. It is easier to trust officials of this caliber than to become truly informed. We must all be teachers all of the time, because this "official" ideology does affect us directly and our families have only us to do the necessary teaching and advocating.

2012 Annual Conference and Initiative

For those of you who call The Liason in Washington, D.C. your "home away from home" I have good news to report. After an extensive search that involved 20 requests for proposals, seven site visits and a survey of past conference participants, VOR has determined that the Liaison, better than other options, meets our needs relative to price, location and service. The comments by past participants were the most helpful in making this decision. We learned that while the cost of a hotel room was one factor, it was not the most important factor. Distance to Capitol Hill was ranked higher, and factors such as personal safety and nearby amenities (especially other restaurant options) were also very important to participants.

The 2011 Annual Conference and Initiative will also be held at the Liaison, June 10 – 14. The 2012 dates are June 8 – 12.

"Housekeeping" Matters

The Every Member Campaign is up and running. This is an easy way for VOR to raise awareness and funds. Please sign up today!

There has also been a tremendous amount of work done by Peter Kinzler, Tamie Hopp and the Legislative Committee to move our bill H.R. 1255. With the Congress in such gridlock, things are difficult but that has not stopped our intrepid team. We appreciate their efforts and hope for a positive outcome.

Lastly, don't forget to visit our website often and make it your home page.

Thank you for your continued support of VOR the only "voice of reason!"

VOR Contact Information

Membership Dues/Contributions

836 S. Arlington Heights Rd., #351
Elk Grove Village, IL 60007
605-271-0445 fax
877-399-4VOR toll free

Executive Director

Julie Huso
3605 W. Ralph Rogers Rd.
Sioux Falls, SD 57108
605-370-4652 direct
605-271-0445 fax
jhuso@vor.net

Director of Govt. Relations/Advocacy

Tamie Hopp
P.O. Box 1208
Rapid City, SD 57709
605-399-1624 voice
605-399-1631 fax
thopp@vor.net

Washington, DC

Larry Innis
529 Bay Dale Court
Arnold, MD 21012-2312
410-757-1VOR phone/fax
LarryInnis@aol.com

The Value of a VOR Membership is now on VOR's website www.vor.net , click "Join"

- ✯ Learn about VOR's Value
- ✯ Membership Benefits
- ✯ 27-year Milestones

WANTED!

Motorcycle for VOR Raffle

Do you now own a Harley Davidson motorcycle, or know a Harley dealer? We're seeking a Harley donation for a VOR raffle. Contact Julie at 605-370-4652 or jhuso@vor.net to help.

Membership/Contribution Form:

Please send dues to—
VOR
836 S. Arlington Heights Rd., #351
Elk Grove Village, IL 60007
605-271-0445 fax
or donate online @ www.vor.net.

Sibling continued from page 5

brother's life depends on it. I am inspired by others I see, people like Tamie and Julie and Mary and so many others in VOR, like the staff and management of Southbury Training School, like my sister and many of the other family members and guardians I have met. I also owe a feast of gratitude to my wife Cristy, who has encouraged me and joined me in taking a more active role in my brother's care and in supporting and participating in VOR.

Books for Siblings

Riding the Bus with My Sister, by Rachel Simon

How to Be a Sister: A Love Story with a Twist of Autism, by Eileen Garvin

Thicker than Water: Essays by Adult Siblings of People with Disabilities, edited by Don Meyer

VOR EVERY MEMBER CAMPAIGN

Name _____

Address _____

City _____ State _____ Zip _____

Telephone _____

Email Address _____

❑ **My contact information has changed**

Membership Categories:

Individual --- $40
Parents' Association --- $200
Professional Assoc./Corp. --- $250

An additional gift/pledge is enclosed for:

___$1,000 ___$500 ___$250 ___$100 ___Other

I would like to support the efforts of VOR with a:

❑ Pledge of $20/month for 12 months for a total of $240, and **pay by check to VOR** -

___Please send me monthly email reminders.

OR

___My $240 for the year is enclosed.

❑ Pledge of $20/month for 12 months for a total of $240 and **pay by credit card** -

___Monthly ($20 will be automatically charged . each month for 12 months)

OR

___Please charge $240 once.

❑ Visa ❑ MasterCard ❑ Discover

Card Number: _____

Expires: _____ CVC (3 digit security) Code _____

Amount to charge: $ _____

Signature: _____

❑ LIMITED TIME OFFER!! Check here if interested in a FREE one-year Digital Subscription to EP (Exceptional Parent) Magazine (internet access required). Upon returning this form and checking this box, we'll forward your name and email address to EP. Offer only for VOR members. Join Today! Expires 12/31/2010.

If the minimum dues requirement poses a financial difficulty, please contact our office in confidence (877-399-4VOR). It is in our best interest that you receive VOR's information, so please call if $40 per year poses a financial hardship. Dec10NL

VOR
Speaking Out for People with Mental Retardation

836 S. Arlington Heights Rd., #351
Elk Grove Village, IL 60007
877-399-4VOR toll free
605-271-0445 fax
www.vor.net

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

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Tamie Hopp 6
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Rapid City SD 57709-1208

Tributes

IN MEMORY

Nancy Barnett
Ruth Barnett
Mary Breiner
Mark Crawford
Regina Cukierski
Heather Kimmel
Mable LeFleur
Amelia Grace Lorang
Jackie MacRae
Marian Snow

IN HONOR

Stephen Bannar
Ryan Donaldson
Peter Kinzler

ONLINE TRIBUTES & MEMORIAL FUNDS

To read about the lifetime advocacy of Marian Snow, Mark Crawford, and Jackie MacRae, please visit www.vor.net/images/Tributes.pdf. Memorial Funds have been set up in Marian and Mark's memories. To contribute, contact Julie at jhuso@vor.net or 605-370-4652.

HELP US HELP YOU

- **Your MAILING LABEL includes your membership expiration date. Please take a look!**

- **Leadership Changes? When your family association elects new leaders, please let VOR know so we can update our records. This ensures VOR's information gets to the right people.**

- **E-Mail Changes? Let us know so we can update our records and you can continue receiving the VOR Weekly E-Mail Update and important alerts.**