

Summer 2007

President's Message

NOTICE:
New VOR address effective Aug. 1.

For dues/donations:
VOR
836 S. Arlington Heights #351
Elk Grove Village, IL 60007
847-258-5273 fax
kluck146@comcast.net

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Progress
by Mary McTernan,
President



VOR has been on a growth path for many years. To help illustrate the significant progress VOR has made in its 25 year history, a chronology of events is included on page 2 of this newsletter. As VOR's resources have grown, so has our effectiveness on behalf of people with mental retardation. It is really quite remarkable how far we have come from where it all started – the home of Marty and Evelyn Pratt.

Current Noteworthy Changes = Continued Progress

On August 1, 2007, VOR closed its office in Rolling Meadows, Illinois. The closure of this VOR office frees a significant amount of resources that will be reinvested in VOR awareness activities and other critical programming. VOR will maintain its offices in Washington, D.C. and South Dakota, and will be opening soon a third office, likely on the East Coast. A toll free number has also been secured: 877-399-4VOR .

New VOR Toll Free Number: 877-399-4VOR

Joanne Kluck will continue serving VOR, helping with accounts receivable/payable and database management. She has served VOR for 18 years as a dedicated employee; we are truly blessed by her willingness to remain involved and supportive of VOR.

The following are VOR's office locations:

Tax Deductible Dues/Contributions

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Govt Relations/Advocacy

Tamie Hopp, Director, Govt. Relations & Advocacy
P.O. Box 1208 * Rapid City, SD 57709-1208
605-399-1624 direct / 605-399-1631 fax
Tamie327@hotmail.com

Washington, D.C.

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

Sad news – Geoff Dubrowsky retires

Due to unanticipated personal reasons, Geoff Dubrowsky voluntarily resigned from VOR service. Even though his tenure with VOR was short, his contributions were astounding:

- February 22-March 2, 2007: Trip to KY and IL,
- April 2007: Trip to Northern California.
- April 2007: Presentation to the Northern Virginia Center Parent's Association.
- April 2007: Trip to Connecticut to meet with Northwestern Mutual representatives.
- June 2007: Single-handedly arranged for VOR's first ever Capitol Hill Reception.
- June 2007: Thanks in large part to Geoff, VOR secures sponsorships to cover all non-staff related costs of the Annual Meeting.
- August 2007: Arranged by Geoff, VOR exhibits for the first time at the National Conference of State Legislatures.
- October 2007: Arranged by Geoff, VOR will join Parents of Autistic Children (POAC) as hosts and beneficiaries of the fundraiser, Golf Outing for Children and Adults with Autism and Other Developmental Disabilities.

For Annual Meeting Sponsors, see pp. 6 – 7.

Welcome Kelly!

Kelly Guesnier has agreed to help VOR with its fundraising needs through, at least, December 31, 2007. With a background in political fundraising, Kelly equates fundraising with "putting on her favorite pair of jeans." She has tremendous experience and the desire to help VOR. To reach Kelly directly, you may contact her at 208-853-1825 or dreamweaverstill@hotmail.com. She welcomes your referrals and fundraising ideas.

We are delighted to have Kelly join the VOR team!

Conclusion

The 25-year chronology shared on page 2 shows vividly the evolution of our organization, from its beginnings in our founder's kitchen to the strong, credible organization it is today! Thank you for being partners in our growth. **V**

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President:
Mary McTernan
Editor: Tamie Hopp

VOR CHRONOLOGY: MILESTONES, 1983 – current (25 Years!)

FY 1983: VOR is founded by Marty Pratt and others from across the country.

FY 1989: VOR's "office" moves from Marty's home to donated office space located at Clearbrook; and Joanne is hired.

FY 1990: Marty Pratt retires as VOR's President and Polly Spare is elected to as President.

FY 1991: VOR hires Jim Enrietto, the organization's second employee.

FY 1993: Represented by Bill Sherman, VOR as *Amicus Curiae* successfully argues in support of family participation in placement decisions in Heller v. Doe, a U.S. Supreme Court case. VOR's proposed "Primary Decisionmaker" language is included in the DD Act. VOR moves to a new office location in Rolling Meadows, Illinois.

FY 1995: VOR hires Tamie Hopp in September 1995 as Office Manager. Her title later changes to Executive Director and then, Director of Government Affairs and Advocacy. Jim Enrietto also retires about this time, but continues volunteering his time with VOR for many more years.

FY 1997: VOR convenes its first Legislative Committee to allow for a more organized and proactive response to legislative and government affairs initiatives. Mary McTernan serves as the Committee's first Chair.

FY 1998: On behalf of VOR, and due to Louise Underwood's leadership, Senator Wendell Ford (D-KY) and Rep. Scotty Baesler (D-KY) introduced S. 1649 and H.R. 3281. This legislation proposed to exempt all Medicaid-eligible disabled persons from mandatory Medicaid managed care. The *Congressional Record* includes Senator Ford's public thank you to VOR and Louise Underwood. Also in this year, VOR hires its first Director of Resource Development, Tom Murray.

FY 1999: VOR submits an *Amicus Curiae* brief in Olmstead v. L.C. 141 organizations join VOR's brief. Later this year, VOR's position with regard to choice is supported by the Supreme Court in its decision, quoting VOR's brief: "Each disabled person is entitled to treatment in the most integrated setting possible for that person - recognizing that, on a case-by-case basis, that setting may be an institution." Also in this year, Polly Spare retires as VOR President after 9 years of service.

FY 2000: Marilyn Straw is elected as VOR's President. VOR submits an *Amicus Curiae* brief in Garrett v. University of Alabama, defending the constitutionality of the Americans with Disabilities Act. VOR's brief is joined by 93 organizations. In an effort to enhance Washington Initiative participation, the Annual Meeting is held in Washington, D.C., immediately preceding the Washington Initiative. Also in this year, VOR secures additional choice language within the "primary decisionmaking" language in the DD Act.

FY 2001: Nancy Ward is elected as VOR President.

FY 2002: VOR moves to a larger office to accommodate a growing organization. Dawn Bisesi & Beth Weinstein are hired.

FY 2003: VOR's peer-reviewed cost comparison study is published in *Mental Retardation*.

Bill Sherman wins a significant victory in People First of Tennessee v. Arlington Developmental Center. A proposed settlement agreement is rejected by the Federal Court due, in part, to the families' objections.

FY 2003/2004: VOR's perspective regarding objective outcome measurements is published in *Exceptional Parent Magazine* and *Mental Retardation* (Mary McTernan and Nancy Ward). In these publications, VOR takes issue with the adequacy of satisfaction measures of quality alone (e.g., questionnaires that ask cognitively disabled persons, "are you happy?").

FY 2005: Mary McTernan is elected as VOR President. The Burke Legal Support Fund is established in Bill Burke's memory with the purpose of ensuring ongoing legal funding for VOR's legal advocacy. VOR enlists the help of the international law firm, Sidley Austin LLP, who has since donated more than \$350,000 worth of legal fees and expenses, helping members in Washington, New Jersey, Illinois (2 cases), Florida and Maryland. Attorney and VOR member Martha Dwyer is recruited to serve as VOR's volunteer Pro Bono Coordinating Counsel. VOR signs the first of several contracts with the Executive Service Corp (ESC) in Chicago to assist with improving VOR's overall infrastructure, from its board, staff and office.

FY 2006: VOR hires its first Washington Representative, Larry Innis. Beth Weinstein resigns and Tony Padgett is hired to VOR's new Director of Resource Development. VOR hosts a Board of Directors retreat in Chicago, facilitated by ESC.

FY 2006/2007: VOR presents public comment, verbally and in writing, to the Administration's Medicaid Commission at hearings in Atlanta (March), Dallas (May), and Washington, D.C. (July, September and November). Our comments focused on the myth of an institutional-bias, accurate cost comparisons between facility and community services, the types of people served in facility-settings and their specialized and intense needs, the abuses that often plague community settings, and the advantages of the community resource center model.

FY 2007: VOR's revenues are 360% more than in 1990. In March 2007, Geoff Dubrowsky officially begins as VOR's Executive Director, with visits to Kentucky and Illinois. VOR's June Annual Meeting is attended by nearly 120 people from 28 states; and 85 volunteers participate in the Washington Initiative, up from an estimated 40 people in 2000. VOR's materials were left with every Congressional office, key offices in the Administration and with national organization allies. On VOR's behalf, Rep. Barney Frank introduced H.R. 2839 in June 2007, a bill aimed at requiring P&A to involve guardians prior to initiating remedies, including class action lawsuits, on behalf of wards with mental retardation and developmental disabilities.

FY 2008: On August 1, VOR's Rolling Meadows office is closed. At this same time, Joanne officially retired after 18 years of dedicated service. Joanne will remain involved with VOR, continuing to help with bookkeeping and database management. Geoff Dubrowsky resigns as VOR's Executive Director, citing personal reasons.

**VOR
Calendar of
Events**

October 22

Golf Outing for
Children and Adults
with Autism and
Other

Developmental
Disabilities at the
Bamm Hollow
Country Club in
Lincroft, NJ. All
proceeds to be
shared equally
between VOR and
Parents of Autistic
Children (POAC).

For more
information,
including a form to
donate or participate,
visit www.vor.net or
www.poac.net.

Nov. 15-17

VOR exhibit at the
World Congress &
Expo on Disabilities,
Washington, D.C.

See
www.wcdexpo.com
for more
information.

June 13-18, 2008

VOR 2008 Annual
Meeting &
Washington
Initiative.

25!

**June 2008:
VOR's 25th
Anniversary.**

An event to
commemorate
VOR's silver
anniversary will be
held in conjunction
with the Annual
Meeting and
Initiative in June
2008, in
Washington, D.C.

Family Rights Bill Introduced!

**If passed, this federal bill will require
Protection & Advocacy and others to inform families before
filing a lawsuit and give opportunity not to participate**

Background: H.R. 2839 is introduced

At VOR's request, on June 22, 2007, Rep. Barney Frank (D-MA) introduced H.R. 2839. As originally introduced, this legislation would have required that state Protection and Advocacy (P&A) agencies give notice to, and obtain the authorization of, an individual (or the individual's guardian) before pursuing remedies, including lawsuits, on behalf of the individual.

NEW! New Development: H.R. 2839 will be revised

During the week of July 16, VOR learned from Barney Frank's Director of Policy, that Rep. Frank will be revising H.R. 2839. VOR leaders were then invited to meet by teleconference with Rep. Frank's legislative counsel to share VOR's perspective and discuss the core principles of the bill. The meeting was very positive and productive. From this meeting we learned that, while Rep. Frank intended to make changes to H.R. 2839, how it would be revised had not yet been decided.

VOR President, Mary McTernan, meets with Rep. Barney Frank

At the request of Rep. Frank, Mary McTernan met with him in his district office near Boston, Massachusetts on August 6, 2007. At this meeting, Rep. Frank indicated he was working on revisions, subject to the review of House legislative counsel.

The revised bill, we learned, will continue to protect the core principles of the original bill, namely, the requirement that P&A speak with families/guardians before pursuing legal remedies, on behalf of family members/wards with mental retardation.

Rep. Barney Frank has pledged his commitment to VOR. We are confident that the revised bill will protect the principles contained in the original H.R. 2839.

Important Next Steps for Choice Advocates

As soon as Rep. Frank re-introduces this legislation – which could be as early as September – securing co-sponsors and the ultimate passage of this bill is **THE PRIMARY VOR GOAL** in the days, weeks and months ahead. We'll need your help to make this happen!

Upon reintroduction, VOR will issue an **Action Alert** to its email network of choice advocates and post the alert to VOR's website at <http://www.vor.net>. The alert will describe the new bill, provide a template letter for your use in securing House co-sponsors, and provide Congressional contact information.

For up to date information, feel free to contact Tamie Hopp at 605-399-1624 or Tamie327@hotmail.com.

Note:

Once revisions are made to H.R. 2839, it will be reintroduced and given a new number. It will no longer be H.R. 2839; a new number will assigned.

Next step for choice advocates

Passage of this legislation is the top VOR priority. As soon as the **new** bill is introduced, we will post an alert on VOR's website at <http://www.vor.net>.

Online Updates

Visit VOR's website often to find out about updates and learn how you can help:

<http://www.vor.net>

Contact Tamie at Tamie327@hotmail.com to receive Action Alerts directly to your email.

Securing co-sponsors and the ultimate passage of this bill is **THE PRIMARY VOR GOAL** in the days, weeks and months ahead!

Stay Tuned!! We're counting on your help to get this legislation passed!!

Legislative Briefs: Summaries of relevant federal legislation

VOR's Positions on Key Legislation

Visit, www.vor.net/2007Leave-Behind.htm, to see what VOR distributed to members of Congress during the 2007 Washington Initiative.

Up to date information on pending federal legislation

Visit, <http://thomas.loc.gov> for copies of federal bills and their status.

Appropriations: Labor, Health and Human Services and Education

The Senate Appropriations Committee approved a bill calling for \$142.2 billion in discretionary spending in FY 2008, while the full House passed a bill calling for \$151.7 billion. These bills include proposed appropriations for the Developmental Disabilities Act programs. The Senate bill proposes a \$20 million increase above FY 2007 amounts, including increases of \$5 million each to State Councils on DD and Protection and Advocacy systems. The House bill calls only for an increase for DD Councils of \$5 million and no increases for the other DD Act programs. The House bill also includes \$10 million for lifespan respite care, and \$50 million for IDEA.

S. 1050, Promoting Wellness for Individuals with Disabilities Act of 2007

Introduced by Senator Tom Harkin (D-IA), S. 1050 proposes new accessibility standards for medical diagnostic equipment and proposes to establish a program for promoting good health, disease prevention, and wellness and for the prevention of secondary conditions for individuals with disabilities. VOR **supports** this important legislation.

H.R. 1279, Direct Support Professional Fairness and Security Act of 2007

Introduced by Rep. Lois Capps (D-CA) and Rep. Lee Terry (R-NE), the Direct Support Professional Fairness and Security Act of 2007 proposes to offer enhanced federal Medicaid funding to states to increase wages for direct support professionals (DSPs) serving people with disabilities. VOR **supports** this well-meaning bill and applauds Congressional efforts to address the direct care work force hiring and retention crisis.

S. 799 and H.R. 1621, The Community Choice Act of 2007 (aka MiCASSA)

Introduced every session since the 105th Congress (1997), this legislation proposes a new **mandatory Medicaid entitlement** for community-based personal attendant care services. CBO estimated that the original bill would cost of \$10-\$20 billion in new federal funding every year and the same mandatory entitlement remains in S. 799 and H.R. 1621. VOR **strongly opposes** S. 799 and H.R. 1621. For States to accommodate this increase in **mandatory** Medicaid expenditures, funding for **optional** Medicaid programs will have to be cut, *i.e.*, 1915(c) Home and Community-Based Services waiver, the state plan personal care services benefit, and ICFs/MR. Sponsors: Senator Tom Harkin (D-IA) and Rep. Danny Davis (D-IL).

CLASS Act Introduced

On July 21, 2007, Senators Edward Kennedy (D-MA) and Tom Harkin (D-IA) (S. 1758) and Reps. John Dingell (D-MI) and Frank Pallone (D-NJ) (H.R. 3001) introduced the Community Living Assistance Services and Supports (CLASS) Act of 2007 that would establish a national long-term care private insurance program, with premiums paid by voluntary payroll deductions. The bill also directs the Secretary of HHS to enter into advocacy contracts with each state P&A system, subject to conflict of interest safeguards. VOR **applauds** the Act's objectives to enable beneficiary independence and enhanced private insurance coverage for long term care services, thereby reducing the reliance on the Medicaid program. VOR **strongly opposes** the bill's provision that requires **exclusive** P&A advocacy service agreements, without regard to whether others may be better qualified, better suited and/or more cost effective in this role.

H.R. 2895, National Housing Trust Fund Act of 2007

Rep. Barney Frank (D-MA), Chairman of the House Financial Services Committee, Rep. Jim Ramstad (R-MN) and 14 bipartisan cosponsors introduced H.R. 2895 which proposes to develop a fund to construct, rehabilitate, and preserve 1.5 million units of housing over 10 years. Funding for this effort would come from a dedicated private source of financing, including Fannie Mae and Freddie Mac profits. According to the Disability Policy Collaboration, "This bill is especially important for the disability community because of the housing affordability and accessibility crisis facing people with disabilities. This crisis has escalated in recent years due in large part to the lack of housing production."

H.R. 3195, Americans with Disabilities Restoration Act

Majority Leader Steny Hoyer (D-MD) and Representative James Sensenbrenner (R-WI) recently introduced the ADA Restoration Act to help address a series of court decisions that have chipped away at the original intent of the law and has seriously weakened protections.

VOR responds to Social Security Crisis

“Most people with severe and profound mental retardation were born with their disabilities. Many of these individuals also experience physical disabilities, complex medical conditions and/or severe behavioral challenges. They need assistance in every aspect of care, including walking, talking, toileting, dressing, transportation, recreation, and therapies. Those who care for them do so with SSI or SSDI (social Security benefits based upon a parent’s earnings). It is essential that these benefits remain, at the very least, at current levels. Any reductions in the benefits they receive could have very serious consequences for their care.

“On behalf of the thousands of people with developmental disabilities and their families that we represent, VOR strongly urges the Subcommittee to approve an appropriation for the Social Security Administration (SSA) for its Limitation on Administrative Expenses (LAE) of, *at a minimum*, the amount allowed in the Fiscal Year 2008 Budget Resolution Conference Report – **\$10.1 billion** (The Commissioner of Social Security requested \$10.44 billion to carry out SSA’s administrative obligations). Funding shortfalls have led to the largest backlogs in disability determinations and appeals in history. Families are torn apart; homes are lost; medical conditions deteriorate; once stable financial security crumbles; and many claimants die while waiting for a decision.” (Source: VOR letter to Senate Appropriations Subcommittee, June 18, 2007; *excerpts*). **V**

Social Security in Crisis: Understaffing Strains Social Security

Staffing at the Social Security Administration will soon be at its lowest level since 1974. The number of disability claims waiting for hearing decisions is at an all-time high. Some applicants wait three to four years for coverage decisions. On average, about 850,000 people visit field offices each week, and some wait two to three hours for help. About 68 million phone calls pour into the field offices each year, overwhelming employees in thinly staffed offices. Offices are closing in California, Connecticut, New York, Texas and Pennsylvania. For every two field employees who retire or quit, Social Security replaces one.

Congress is trying to address the problems. The House Appropriations Committee has recommended that Social Security receive \$100 million more than the White House requested, and the Senate Appropriations Committee has proposed a \$125 million increase. President Bush proposed that Social Security, which has about 61,400 employees, receive \$9.6 billion for operations in fiscal 2008. That fell short of the \$10.44 billion that the agency calculated it would need. Congress does not allow it to dip into the Social Security trust fund for administrative and operating costs.

Social Security staffing will have declined by 4,000 positions over two years ending Oct. 1. Even with modest Congressional support over and above what the President requested, funding, if approved, will only allow the agency to hire 1,000 employees in the next year, making only a small dent in the workload. The agency's problems could become more serious in the next few years, as millions of baby boomers apply for retirement benefits and file disability claims (Source: *Washington Post*, Wednesday, July 25, 2007). **V**

California funding crisis: Safety net for Medi-Cal has run out of cash

A \$2 billion fund created to keep money flowing to Medi-Cal providers when a legislative deadlock delays a new state budget has hit empty, reducing payments to HMOs and threatening payments to hospitals and nursing homes. Medi-Cal is the state version of Medicaid, the government program that provides health care coverage for the poor and disabled.

The state has been without a budget since the new fiscal year began July 1, blocked by Senate Republicans who are demanding deeper spending cuts. The \$2 billion Medi-Cal fund, created in 1998, gets \$1 billion from the state and a \$1 billion federal match to keep money flowing to the providers of vital health care services when there is no state budget.

For hospitals that serve a high number of Medi-Cal patients, such as rural, public, children's and other safety-net hospitals (e.g., state developmental centers) this can amount to 60 percent or more of their revenues. Small homes that care for the developmentally disabled, typically with just six beds, often receive all of their funding from Medi-Cal.

“The impasse must end,” said Jim Gomez, President of the California Association of Health Facilities. “If the state budget is not enacted within the next few days, the state will not be able to pay providers for 24-hour care for nearly 6,000 developmentally disabled individuals living in more than 1,000 community-based small group homes throughout California” (Source: *Union-Tribune*, July 28, 2007).

Some state developmental centers are also suffering steep staffing shortages, although it is questionable whether the pending budget will adequately address these shortages. Families have lobbied the state legislature and Administration for adequate funding. **V**

What do states receive?

If awarded an MFP grant, a state will receive 100% federal financing for one year (only) to serve an individual transferred from an institution to the community under the MFP program. Normally, these Medicaid costs are split between the federal government and the state. The amounts received by each state differ based upon the state's proposal.

These states received MFP grants:

AR CA CT DC DE
GA HI IA IL IN
KS KY LA MD MI
MO NC ND NE NH
NJ NY OH OK OR
PA SC TX VA WA
WI

MFP Program Objectives

1. Rebalancing – increase use of home and community based services, instead of institutions.

2. Money Follows the Person – eliminate barriers that prevent or restrict the flexible use of Medicaid funds.

3. Continuity of Service – Increase the ability of the State Medicaid program to assure continued provision of home and community based long term care services.

4. Quality Assurance and Quality Improvement.

For more information about MFP grants, visit: www.cms.hhs.gov/DeficitReductionAct/20_MFP.asp.

Money Follows the Person (MFP) Rebalancing Demonstration

Enacted by the Deficit Reduction Act of 2005, the Money Follows the Person (MFP) Rebalancing Demonstration initiative will assist States in their efforts to reduce their reliance on institutional care while developing community-based long-term care opportunities. 31 grants were awarded in 2007 to 31 States; grant awards totaled \$1,435,709,479 for the purpose of transitioning 37,731 individuals out of institutional settings.

The people and places

MFP grants will be used to transition Elderly, MR/DD, physically disabled, mentally ill, and dual-diagnosed individuals from nursing homes or intermediate facilities for persons with mental retardation (ICFs/MR). People with MR/DD make up 20% of the individuals to be transferred using MFP grants. It is not clear how many of these individuals will be transitioned from nursing homes, and what percentage will be transferred from ICFs/MR.

MFP Operational Protocol

The state's receipt of its approved grant is conditioned upon its submission of an Operational Protocol. The state's Operational Protocol must provide enough information to provide the Centers for Medicare & Medicaid Services (CMS), the State's Project Director, and stakeholders with an understanding of the operation of the demonstration.

Your Role: Get involved!

As has been mentioned in *The Voice* in past issues, you are strongly encouraged to get involved in the implementation of your state's MFP program. The MFP statute requires that states formally involve stakeholders in the implementation of their MFP programs. Thus, most States have formed MFP committees, workgroups, or task forces. Important decisions will be made by these groups, including how individuals are assessed for transition and how written "informed consent" for transfer is ensured. CMS is requiring that each state, "ensure all demonstration participants are aware of all aspects of the transition process, have full knowledge of the services and supports that will be provided [including after the MFP grant expires], and are informed of their rights and responsibilities as a participant of the demonstration." Your involvement now at the state level is critical.

VOR will be reviewing CMS' Operational Protocol which, although already released, is described as "DRAFT (Working with the grantees, CMS will continue to modify this document)." In response to questions and feedback raised in a teleconference with CMS representatives, VOR was encouraged to submit written comments. VOR staff can also assist you with your state level MFP activities. Contact Tamie at 605-399-1624 or Tamie327@hotmail.com with any questions.

For more 2007 Annual Meeting Sponsors, see page 7.

THANK YOU PARTICIPANT SPONSORS!!!

These organizations and individuals provided the trip costs for one or more 2007 Annual Meeting and Washington Initiative participants.

ACTION for RHCs (WA)	Fairview Family and Friends (CA)
Advocacy Network, Inc (MA)	The Fernald League (MA)
Anonymous Donor	Friends of Fircrest (WA)
Association at Hunterdon Developmental Center (NJ)	ForConn (CT)
The Association for the Mentally Retarded at Agnews (CA)	Elbirda Haley (KY)
Bellefontaine Habilitation Center Parents Association	Idaho State Council on Developmental Disabilities
California Association of Psychiatric Technicians (CA)	Idaho State School and Hospital Parent/Guardian Assoc.
Steve Colbert (AR)	Keeping Our Families Together (CA)
Concerned Citizens for the Mentally Retarded (MA)	Massachusetts COFAR
Concerned Families of Hazelwood ICF/MR (KY)	Northeast Care Center, Inc. (OH)
Conway Human Developmental Ctr. Parents Group (AR)	Novack Burnbaum Crystal LLP (NY)
Conway Human Develop. Ctr. Volunteer Council (AR)	Parents and Friends of Ludeman Center (IL)
Council on Mental Retardation (KY)	Parents Coordinating Council & Friends (Lanternman) (CA)
Developmental Disabilities Nurses Association	Parent Hospital Association of Sonoma Develop. Ctr. (CA)
David, Leni, Carly, Marlo and Rita Engels,	Pincrest Parents Association (LA)
In memory of Jordy Engels	Sacramento Association for the Retarded (CA)
	Wisconsin State Employees Union AFSCME Council 24

Thank You Sponsors!!!

Platinum - \$10,000

Rosewood Center Auxiliary

Gold - \$5,000

Susan M. Hopkins-DiMeo
Literacy Fund

Walter E. Fernald Corporation
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VOR 2007 Annual Conference and Washington Initiative

On June 9, 2007, 120 VOR members from 28 states enjoyed three inspiring speakers whose presentations illustrated well, "Policymaking from State to Federal: A focus on the issues and the role of Advocates," the theme of VOR's 2007 annual conference in Washington, D.C.

Mary McTernan, VOR's President, kicked off the event with a presentation that highlighted VOR's accomplishments in the past year and provided updates on what's to come. A summary is provided in the President's Message in this issue of *The Voice*.

 **Eileen Elias**, M. Ed., Deputy Director of the U.S. Department of Health and Human Services Office on Disability (OD) spoke about the Surgeon General and OD's Call to Action to improve the health and wellness of persons with disabilities. The Call to Action involves a significant number of healthcare professionals, policy and decisionmakers, and a wide variety of other individuals and organizations interested in bringing healthcare services to people with mental retardation and other disabilities. For more information on the CTA and how you can help, visit, http://www.hhs.gov/od/about/fact_sheets/surgeongeneralcta.html.

 **Matt Salo**, Director of Health and Human Services Committee, National Governors Association provided a perspective on how state policy is directly tied to federal policy, in particular Congressional funding priorities (e.g., Medicaid).

 **Greg Giordano**, Chief Legislative Assistant to Florida State Senator Mike Fasano (R-11) (Majority Whip), focused on effective grassroots advocacy at the state level, using S.B. 402 (introduced on behalf of VOR's Florida affiliate, DSI Supporters, Inc.) as an example. He emphasized that effective grassroots advocacy begins with building positive relationships with legislators and their staff long before the introduction of any legislation. S.B. 402, which would require that closure decisions be made by the Florida Cabinet, rather than by a single agency, and formally include the family's perspective, came about due to a friendship between Don Stover (VOR member) and Greg Giordano. Greg knew Don to be an advocate with integrity. Greg's presentation was inspiring; S.B. 402 was provided to participants as a template for use in other states.

Third Annual Friday Night State Reports

Participants also enjoyed the Third Annual Friday Night Forum, focusing on Reports from the States. **A report from this session will be published soon.**

2007 Washington Initiative

More than 80 participants from 28 states distributed VOR's presentation folder to every Congressional office. VOR's primary issue for the 2007 Washington Initiative was the

Reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act (DD Act). This is the federal law that creates state Protection and Advocacy programs and DD Councils. Although not yet introduced, the DD Act is scheduled to be reauthorized in 2007, although some experts believe it won't be reauthorized until next year. The House and Senate have proposed funding for DD Act programs through 2008.

Success! Soon after returning from Washington, D.C., VOR received the good news that Rep. Barney Frank, a well-respected member of the majority party, had introduced H.R. 2839. Consistent with VOR principles, this bill requires that P&A seek guardian authorization before legally representing any individual. More information about H.R. 2839, including anticipated revisions, is on page 3. **V**

For VOR's DD Act Reauthorization reform proposals, visit
<http://www.vor.net/DDAct2007.html>

For VOR legislative positions distributed to Congress, see
www.vor.net/2007Leave-Behind.htm

Illinois: Lincoln may be closer to reopening

The Illinois Health Facilities Planning Board gave its approval to allow the state to operate four, 10-bed homes for developmentally disabled residents on the grounds of the former Lincoln Developmental Center. The institution was shuttered five years ago by former Gov. George Ryan. During his 2002 campaign, Gov. Rod Blagojevich promised to reopen the institution, but backed off after opponents pushed to move the state toward providing smaller, community-based settings for people with MR/DD. As a compromise, officials agreed to build the four homes on the 103-acre grounds at a cost to taxpayers of about \$4.6 million. But, they have sat empty and unused, costing the state nearly \$1 million per year to keep from deteriorating. The Governor hopes to get funding to operate the four homes in this year's budget, which remains unfinished (Source: *Pantagraph*, July 25, 2007). **V**

State News

South Carolina: Abuse/Neglect Investigations

The Vulnerable Adults Investigations Unit, which functions through the State Law Enforcement Division (SLED), was created under a 2006 law. Previously, the Mental Health and Special Needs departments handled abuse investigations internally, using their own public-safety authorities. SLED, an outside agency, now must investigate all suspicious deaths that occur within facilities operated by or under the Departments of Disabilities and Special Needs and Mental Health. The scope of the new law covers adults who are receiving care in private homes contracted by the agencies. The law establishes "mandatory reporting" and put in place a 24-hour hotline to report allegations of abuse or neglect (Source: *The State*, Jan. 17, 2007). **V**

Connecticut: Abuse/Neglect Investigations

The Commissioner of DMR, who has established a 0% toleration policy against abuse/neglect, has required that the DMR Division of Investigations report directly to him, not to any other entity within DMR. The Commissioner is assured that investigations are conducted in an independent manner by having the Division of Investigations commanded and directed by a Connecticut State Police Captain, and a professional investigator and manager, who works with DMR, but reports to and works for the Department of Public Safety, an outside agency (Source: *Council Meeting*, June 14, 2007). **V**

Massachusetts: Fernald families await Judge's determination

In early June, the State submitted its arguments in the decades-old *Ricci* litigation as to why it is within its discretion to close Fernald Developmental Center. Judge Tauro has consistently supported the residents' right to be served at Fernald and has required that individuals transferred must receive "equal or better" services in the community. This Spring, Michael Sullivan, who was ordered by Judge Tauro to review past transfers, found that while the state has thus far met the "equal or better" test, "residents in our community homes are at greater risk of being abused and/or neglected." Sullivan's report also suggested harder to access medical care in the community, whereas Fernald has a range of medical and psychological professionals on site at any given time. He recommended that Fernald remain open for residents who wish to live out their lives there. A ruling by Judge Tauro is expected soon (Source: *Daily News*, June 2004). **V**

North Dakota and Montana: Funds for direct care workers proposed

Governors in North Dakota and Montana presented budgets that include proposals for increased direct care worker pay. In **Montana**, Governor Schweitzer proposed an \$18 million increase over the next two years to provider agencies to increase direct support workers' pay. In **North Dakota**, Governor Hoeven proposed increasing funds for direct support workers by giving them a \$.60/hour wage increase (Source: *Community Services Reporter*, February 2007; see <http://www.nasdds.org>, for subscription information). **V**

Federal bill requires background checks

S. 1577, the Patient Safety and Abuse Prevention Act of 2007, introduced by Sen. Herb Kohl (D-WI) seeks to amend the Medicare Prescription Drug Act of 2003 to provide for nationwide expansion of background checks on direct patient access employees of long-term care facilities or providers.

WCD EXPO
World Congress & Expo on Disabilities

Thursday - Saturday, Nov. 15 - 17, 2007
Washington, DC, Convention Center
www.wcdexpo.com

The WCD Expo, the world's leading disability event, is dedicated to improving the lives of people with disabilities, their families and the professionals who work with them. Over 200 exhibitors, **including VOR**, will share their information with more than 5,000 attendees – educators (25%), medical professionals (22%), family members/caregivers (34%), and persons with disabilities (20%). Visit <http://www.wcdexpo.com> for conference information.

Supreme Court: Parents don't need lawyers in education cases

Parents need not hire a lawyer to sue public school districts over their children's special education needs, the Supreme Court ruled. The decision came in the case of an autistic boy from Ohio, whose parents argued they were effectively denied access to the courts because they could not afford a lawyer. Federal law gives every child the right to a free appropriate public education, which in the case of special needs children sometimes means enrollment in a private facility. But most federal courts had concluded that parents who are not lawyers and who want to challenge decisions have to hire an attorney to represent them. Justice Anthony Kennedy, writing for the court, said parents have legal rights under the Individuals With Disabilities in Education Act, the main federal special education law. The case number is *Winkelman v. Parma City School District*, 05-983. (Source: *The Associated Press*, May 21, 2007)

Court Decision: Mental retardation not an ADA disability

In the case of *Littleton v. Wal-Mart Stores, Inc.*, the Court of Appeals for the Eleventh Circuit, in an unpublished opinion from May 11, held that an individual with mental retardation did not have a disability under the Americans with Disabilities Act. With guidance from the Alabama Independent Living Center, Mr. Littleton interviewed, but was not hired, for a job as a cart-push associate at Wal-Mart. While acknowledging his intellectual disability, in the Court's analysis, Littleton, who receives Social Security benefits because of his disability, was found not to be substantially limited in major life activities. "We do not doubt that Littleton has certain limitations because of his mental retardation. In order to qualify as 'disabled' under the ADA, however, Littleton has the burden of proving that he actually is, is perceived to be, or has a record of being substantially limited as to 'major life activities' under the ADA. It is unclear whether thinking, communicating, and social interaction are 'major life activities' under the ADA," the court wrote. (Source: AAPD, May 2007). (Carlson v. Liberty Mut. Ins. Co., 11th Cir., No. 06-15417, unpublished opinion 6/7/07) (Source: BNA, June 25, 2007, Vol. 12, No. 118). **V**

Legal Briefs

Choices for a Lifetime, Options for All: Summary of VOR's Legal Activity since 2004

VOR's *Choices for a Lifetime, Options for All* legal advocacy program is a board-directed initiative to address the increased legal threat to some publicly-financed residential supports for people with profound mental retardation.

- VOR has filed "Friend of the Court" Amicus Curiae briefs in federal cases in **Ohio**, **Massachusetts** and **Florida**.
- VOR provided \$10,000 to support the families' legal efforts in a federal case in **Tennessee**, and \$3,000 in a federal case in **Arkansas**, recognizing these cases' national significance.
- In **Illinois**, pro bono attorneys, secured by VOR, filed a Motion to Intervene which was ultimately denied by the District Court (and affirmed on appeal). In a second **Illinois** action, VOR arranged for pro bono counsel to help explore the viability of a legal action relating to alleged calculated under-staffing at state operated facilities serving people with mental retardation. Issues pending include whether a private right of action exists in Medicaid relating to quality of care concerns.
- In **Maryland**, a VOR-arranged pro bono attorney is helping a mother on her quest to secure specialized residential care for her daughter continues in what VOR hopes will be an important test case for choice in Maryland. In Maryland, VOR also provided significant staff support in drafting responses to state legislative issues that relate to the pending legal challenge in which we are also involved. Support includes reviewing a Disability Transition Report, and preparing for our state affiliate a written response, rebuttal and minority report (3 separate submissions).
- In **Florida**, families lost their bid for intervention, but have pursued legislation to address injustice of excluding families from critical decisions, as well as options to maintain residential care at a state facility slated to be closed, due to the lawsuit. In this situation, VOR has provided extensive advocacy beyond the families' bid for intervention, including grassroots advocacy training, co-hosted by Sidley Austin; support in organizing a new statewide grassroots advocacy organization to respond to threats; and significant staff support relating to the introduction of legislation and other advocacy needs.
- In **New Jersey**, VOR arranged for an attorney to review the state's individual annual planning process (IHP), including a state directive to include in every IHP a notation of community appropriateness, regardless of individual needs, choice, or guardian choice.

Home health care workers not entitled to minimum wage or overtime pay

Home health care worker, Evelyn Coke, filed a claim alleging she was denied overtime and was not paid a minimum wage for her work as a "home health-care attendant." The Supreme Court justices reversed the Second Circuit opinion, which sided with Cook, and explained that the Labor Department's (DOL) interpretation of its regulations was within its responsibility as an administrative agency because Congress left it to DOL to create regulations, including the exclusion of home health care workers from overtime and minimum wage rules.

Sen. Edward M. Kennedy (D-Mass.), chairman of the Senate Health, Education, Labor and Pensions Committee, said in a June 11 statement after the ruling that he intended to look for a possible legislative fix. "Today's Supreme Court decision highlights a significant gap in the protections of our laws, and I plan to work with my Senate colleagues on a fair solution that treats these hardworking caregivers with the dignity and respect they deserve," Kennedy said. (Long Island Care at Home v. Coke, U.S., No. 06-593, 6/11/07) Source: BNA: June 12, 2007, Vol. 12, No. 112). V

Louisiana and DOJ Settlement Dismissed

Judge hails state's achievements in improving conditions at developmental centers

U.S. District Court Judge James Brady personally thanked Louisiana and the Department of Justice (DOJ) last week on behalf of all Louisiana citizens for what he called an "exceptional job" of improving conditions at the state's two largest residential facilities for people with developmental disabilities. The judge's statements came as he signed a ruling, effectively dismissing a lawsuit regarding the conditions at Pinecrest (Pineville) and Hammond Developmental Centers. The Settlement Agreement, filed on January 12, 2004, was thereby terminated on June 15, 2007, on the grounds that Louisiana has substantially complied with all provisions of the Agreement.

"I can't tell you... how pleased I am as a citizen of this state for this remarkable achievement," Judge Brady said. "You know, I handle many, many cases and it's very, very seldom – in fact, I don't think it's ever happened – where DOJ, the federal government, comes in and says what the State of Louisiana is doing is extraordinary, positive, exceptional, the best, phenomenal."

The dismissal of the lawsuit was requested by DOJ. The Memorandum in Support of the Parties' Joint Motion to Dismiss noted the relationship between the DOJ and Louisiana, saying the Office for Citizens with Developmental Disabilities and the Developmental Centers "have always been collaborative and productive, since the Settlement Agreement was filed. All parties agree that the State of Louisiana is in substantial compliance with all provisions... [and] has achieved significant progress towards improving meaningful outcomes for residents in all critical areas."

Since the Settlement Agreement was filed in 2004, the Office for Citizens with Developmental Disabilities and the two Developmental Centers have accomplished great improvements in areas including better staff-to-client ratios, improved psychological services, protection from harm, basic care, psychological services, restraints, psychiatric care, medical care, dental care, nursing care, nutritional and physical supports/therapeutic interventions, integrated day services and transition of a number of people from the facility to more integrated community residential settings. Community-based learning has been implemented, affording individuals greater access to the community in recreation and other activities. For individuals who are non-ambulatory, the State has developed new community homes that are comfortable, spacious and well-suited to each person's needs. For those continuing to need services and wishing to remain in the Developmental Centers, meaningful work opportunities on and off campus have been increased and now include partnerships with local businesses where employees deliver a variety of services.

Governor Kathleen Blanco says she is also proud of the example being set by this case. "They rose to the challenge presented to them, and should be considered a model for other state agencies to look toward when faced with similar struggles." V

LA and DOJ: Family involvement is key to success

Family communication with DOJ representatives was a critical factor in the successful outcome of this DOJ lawsuit. Paula Millhollon and Doris Pitre are to be commended for their dedication to keeping the family perspective and the right of choice, central to the ultimate outcome of this lawsuit. V

Resource Centers: LA's Future

The future focus for the State will now be the transformation of Louisiana's public institutions into resource centers, settings where technical assistance can be obtained in the community, including clinics and short-term crisis units for people who have developmental disabilities. Transforming the centers into resource centers was a priority for family advocates. V

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Note:

As of August 1, 2007, the Rolling Meadows, IL office is closed.

VOR Weekly E-Mail Update Available Online

<http://www.vor.net/current.htm>

(updated weekly)

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, attn: Tamie Hopp, P.O. Box 1208, Rapid City, SD 57709; Tamie327@hotmail.com.

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Aug07NL

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