

Spring 2008

President's Message

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Don't let this historic opportunity slip by us: Help get H.R. 3995 passed



By Mary McTernan President

6,881. That's our competition. That's how many U.S. House bills have been introduced in the 110th Congress. So far, only 17% have passed the House and far fewer will ever become law.

With 6,881 bills to consider, is it any wonder why every VOR member must be in touch with their U.S. Representative (again and again if necessary) to ensure they know about H.R. 3995 and know that constituents support H.R. 3995.

Already our collective advocacy is paying off. At the time I am writing this, we have 18 cosponsors. In every case, it was the call, letter, and visit - sometimes all 3 and more than once! -- by a constituent(s) specifically asking his/her U.S. Representative to cosponsor H.R. 3995.

As the sponsor of H.R. 3995, Rep. Barney Frank, has said, "Now people have to go and talk to their congressman and/or some high ranking aide. Each person must convince his/her own congressman. Anyone can get an appointment . . . That's it!!"

Yes, getting a bill passed in Congress is hard work, but it is necessary work to help ensure resident and family choice in litigation against ICFs/MR. Thank you for all you are doing in support of H.R. 3995.

Upcoming Appointment opportunities!

March 17-28: Spring District Work Period
Members of Congress will be working in their district offices near you, March 17-28. This is a perfect opportunity to request an appointment with your representative.

Anytime!!

Some members of Congress dedicate Fri-

About H.R. 3995

If passed, H.R. 3995, sponsored by Rep. Barney Frank (D-MA), will insure individual and family choice in federally funded class action lawsuits against ICFs/MR. The bill requires the class action lawyers (usually Protection & Advocacy) to notify the facility they intend to sue, and the facility to notify the residents and guardians. Residents and guardians can opt out of the lawsuit, or do nothing and join in. See page 2 for more details.

What about the Senate?

VOR is actively seeking a Senate sponsor, with several Senate offices currently studying the House bill. We welcome any suggestions/connections you have!

Questions? Resources? Help?

Contact Tamie at 877-399-4VOR, 605-399-1624, or Tamie327@hotmail.com for questions about H.R. 3995 or the VOR Annual Meeting and Washington Initiative.

days, weekends, and Mondays, working at their district offices, and all have legislative aides dedicated to health and disability issues who can meet with you.

If you need help identifying your U.S. Representative, or need district office contact information, contact Tamie Hopp at 605-399-1624 or Tamie327@hotmail.com. You can also find district contact information at http://www.congress.org.

VOR Annual Meeting and

Washington Initiative: JOIN US!!

Full details about VOR's annual conference and visit to Capitol Hill is found on pages 10 and 11, including a registration form. Not only do we have an excellent program lined up for the Annual VOR conference, but the Washington Initiative provides us with an EXCELLENT opportunity to advocate in support of H.R. 3995.

Please join us. Numbers count!



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President: Mary McTernan
Editor: Rochelle Hagel

H.R. 3995 Barney Frank's "Family Rights" Bill

Medicaid: Proposed regulations spark controversy

H.R. 3995 CO-SPONSORS to-date:

- Rep. Charles Boustany, Jr. (D-LA)
- Rep. Michael Capuano (D-MA)
- Rep. Stephen Cohen (D-TN)
- Rep. Bob Etheridge (D-NC)
- Rep. Charles Gonzales (D-TX)
- Rep. John Larson (D-CT)
- Rep. Stephen Lynch (D-MA)
- Rep. Doris Matsui (D-CA)
- Rep. James McGovern (D-MA)
- Rep. Gary Miller (R-CA)
- Rep. Brad Miller (D-NC)
- Rep. James Moran (D-VA)
- Rep. Ron Paul (R-TX)
- Rep. Todd Platts (R-PA)
- Rep. Ted Poe (R-TX)
- Rep. Christopher Shays (R-CT)
- Rep. Pete Stark (D-CA)
- Rep. Carol Shea-Porter (D-NH)
- Rep. Lynn Woolsey (D-CA)
- Rep. Tim Walberg (R-MI)
- Rep. Debbie Wasserman Schultz (D-FL)

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Visit

<http://www.congress.org>
and enter your zip code

OR

**Contact Tamie at
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Tamie327@hotmail.com

Your advocacy is still needed!

VOR and its members are working hard to secure support for H.R. 3995, and get it passed!

If passed, H.R. 3995, introduced by Rep. Barney Frank (D-MA), will help assure individual and family decision-making in federally-financed class action lawsuits against Medicaid-certified and funded Intermediate Care Facilities for Persons with Mental Retardation (ICFs/MR). H.R. 3995 requires that before lawsuits against ICFs/MR can be filed, residents and their legal guardians must receive notice of the proposed lawsuit and be given an opportunity to opt out before the lawsuit is filed.

We need your help! Together, we must continue to work to secure many more H.R. 3995 cosponsors.

As Rep. Barney Frank has confirmed himself, **PERSONAL VISITS** are absolutely necessary to secure H.R. 3995 cosponsors. Your representative has a district office in your city or very near where you live.

VOR can help

VOR has developed a number of advocacy materials in support of H.R. 3995 that you can share with your congressman/woman. VOR can also help you identify your U.S. Representative and find contact information for you. We are here to help. Just contact Tamie at 877-399-4867 (toll free); 605-399-1624 (direct); or Tamie327@hotmail.com.

*VOR will help in
every way, but
YOU as the
CONSTITUENT,
need to CALL,
WRITE and
MEET with your
U.S.*

*Representative.
THANK YOU!!!*

In the past year the Bush Administration has moved forward with significant changes to the Medicaid program via rule-making. Taken together, six new regulations could result in an estimated \$12 billion reduction in federal Medicaid spending over the next five years according to the regulatory impact statements prepared by Centers for Medicare and Medicaid Services.

The proposed regulations relate to (1) Government provider cost limits; (2) Graduate Medical Education; (3) Rehabilitation services, including coverage for day habilitation services for people with DD; (4) Medicaid coverage for school administration (relating to outreach, enrollment and EPSDT) and transportation costs; (5) Outpatient Services; and (6) case management coverage.

The Administration views the estimated five year reduction in federal Medicaid spending as a very small share of expected Medicaid spending over the next five years.

However, members of Congress, states, beneficiaries and providers have raised concerns that these changes could have serious negative consequences and may be inconsistent with Medicaid policies enacted by the Congress.

States have also raised concerns that estimated federal "savings" actually represents a shift in costs to the states (i.e., states would either have to use state-only funds to maintain programs or terminate critical services). In fact, the House Oversight and Government Reform Committee has reported that it estimates that states stand to lose almost \$50 billion in five years, a figure far larger than what the Administration reported. This cost shift to states would occur when many are already expected to face budget shortfalls due to the weakening economy. States and advocates have also questioned whether these proposed regulations go beyond Congressional intent for the Medicaid program, and thus beyond the agency's rulemaking authority. Congress is also raising questions. It has already imposed moratoriums on four of the six rules, and the effect of these regulations was the subject of a November 2007 Congressional Hearing.

President's budget calls for cuts to Medicare, Medicaid, Social Security Administration

In his proposed 2009 federal budget, President Bush calls for \$91 billion Medicare savings and \$14 billion in savings from Medicaid, by curbing its growth. Most of the Medicare savings in the budget would be achieved by reducing the annual update in federal payments to hospitals, nursing homes, hospices, ambulances and home care agencies. These figures do not include tens of billions of dollars that Mr. Bush wants to save through new regulations. Such rules are not subject to approval by Congress, but could be revised by a future administration.

President Bush has repeatedly said that the costs of Medicare

and Medicaid are unsustainable. The two health programs account for nearly one-fourth of all federal spending, and their combined cost — \$627 billion last year — is expected to double in a decade. (*New York Times*, Jan. 31, 2008).

President Bush also proposed more than \$100 million in cuts from the SSA's administrative budget. Advocates are strongly opposed to SSA cuts, stating that historic under-funding of SSA field offices has led to a backlog of 753,000 disability claims waiting to be considered, increasing claim processing times. They also cite the 76 million baby boomers entering the system, say-

Federal regulations ("rules") are not subject to approval by Congress, but could be revised by a future administration.

ing that further cuts to the SSA budget "could prove to be disastrous." (Source: AFL-CIO, Feb. 12, 2008).

Congressional Democrats have pro-

nounced the President's budget dead on arrival, and they have no reason to make unpopular cuts in this election year.

The President proposes to level fund DD Act programs in 2009

If the President gets his way, the programs which are authorized to receive funding in the Developmental Disabilities Assistance and Bill of Right Act will get the same in 2009 as they did in 2008 ("level funding"). The President's proposed budget

includes \$37 million for University Centers for Excellence in DD; \$72 million for state DD Councils; \$39 million for state Protection and Advocacy agencies; and \$14 million for Projects of National Significance, including "Family Support." In contrast, DD

Councils have asked for a 10% increase, and P&A's seek a 15% increase in federal funding.

H.R. 5110, the Social Security Customer Service Improvement Act

To keep SSA offices open, advocates are supporting H.R. 5110, introduced by Rep. Brian Higgins (D-NY). The bill would give Congress additional oversight of Social Security Administration (SSA) staff levels, office closures and budget estimates. If enacted, the bill will require the SSA Commissioner to submit the agency's budget directly to Congress and the President without revisions, so the President can't change it. SSA would not be able to close field offices until 180 days after submitting to congressional committees a report justifying the selection of offices for closure. (Source: AFGE press release, Feb. 11, 2008).

Related news:

Bill introduced to delay implementation of Medicaid Case Management rule

In late January, Senator Norm Coleman (R-MN) introduced S. 2578, which calls for a moratorium on the implementation of the Medicaid Case Management rule until April 1, 2009.

Implementation of proposed rules relating to provider cost limits, graduate medical education, and Rehabilitation coverage, are already subject to Congressional moratoriums.

For an overview of the proposed new regulations and their impact, visit <http://www.kff.org/medicaid/upload/7739.pdf>.

What is the difference between Medicaid and Medicare

Medicare is an insurance program that serves people over 65 regardless of their income, younger people with disabilities and dialysis patients.

Medicaid is a medical assistance program. Under Medicaid medical bills are paid from federal, state and local tax funds. This program serves low-income people of every age.

the voice Spring 2008

**West Virginia:
West Virginian sues
for access
to community services**

Shawn Shumbera, a 27-year-old West Virginian with developmental and other disabilities who has resided in a hospital since 2001, filed a class action lawsuit in August 2007, alleging that the state (defendant) "has a pattern and practice of denying recipients and applicants to the Medicaid MR/DD Waiver Program due process." (Source: NASDDDS, Litigation Updates, January 2008). *The case is Shumbera v. Walker.*

**Virginia: State blocks
abuse investigations**

The Virginia Office of Protection and Advocacy (VOPA) has filed a lawsuit against the state, alleging that the state interfered with investigations of possible abuse. The lawsuit relates to VOPA's request to access to certain facility resident records. The state claims that the records are protected by the peer review privilege. VOPA contends that courts have ruled that organizations like VOPA have wide access to patient records, including records which are claimed to be covered by the "peer review" privilege. (Source: VOPA, Dec. 7, 2007).

**California:
Decision to certify class stands**

The Court of Appeals for the First Appellate District reversed a trial court judgment, saying that the district court's "order denying class certification cannot stand..."

The state and family intervenors appealed to the California Superior Court, requesting that the District Court decision denying class certification be reinstated. Unfortunately, in early January 2008, the Superior court declined to accept the appeal, leaving class certification intact.

In support of the family intervenors and the state, VOR had filed with the California Superior Court a "letter of intent," which urged the Superior Court to accept the appeal and reverse the appellate court's decision to certify the class.

VOR believes that every individual is unique and must be treated accordingly

"VOR believes that every individual is unique and must be treated accordingly . . . VOR submits that the Court of Appeals' opinion improperly disregards an actual and substantial conflict among the class members; namely, that a significant number of class members do not wish to forgo the right to institutional care."

California Protection and Advocacy, Inc. represents the plaintiffs in this case, who seek to represent more than 7,000 MR/DD California citizens who are receiving facility-based care, or are "at risk" of facility placement. *The case is Capitol People First v. Department of Developmental Services (DDS), and the trial is set for early March, 2009.*

**Delaware: Residency requirement
for Medicaid may be unconstitutional**

On September 11, 2007, a federal district court held that Delaware's residency requirements for Medicaid eligibility unconstitutionally infringes upon the plaintiff's right to travel.

Plaintiff Marianne Duffy is a North Carolina resident with developmental disabilities whose parents relocated to Delaware. Upon application for Medicaid residential services for their daughter in Delaware, state officials (defendants) refused coverage based on the fact that Duffy was not a resident.

"[O]n their face, the state regulations appear to trap Duffy in North Carolina," said the court. "Even if Duffy could become a resident in the manner prescribed by the Defendants, it is unclear whether a regula-

tory scheme that forces a prospective resident to go through the extra step of paying for private placement before becoming eligible for Medicaid is constitutional," the court added. *The case is Duffy v. Meconi.*

**Washington: High Court rejects regulation,
reduced aid for disabled in 'shared living'**

The Washington State Supreme Court ruled in May 2007 that the State's regulation which reduces the number of hours of paid aid available to disabled individuals by 15 percent when they are in a "shared living" arrangement is invalid because it violated the Medicaid law's comparability requirement.

According to federal law, "The medical assistance a state provides for any categorically needy individual 'shall not be less in amount, duration, or scope' than

the assistance provided to any other categorically needy individual," said the court. Further, the 15 percent reduction "across the board for all recipients who live with their caregivers does not address, and in fact ignores, the realities of the recipients' individual situations." *The case is Jenkins v. Washington Department of Social and Health Services.* (Source: BNA, Volume 12 Number 88, Tuesday, May 8, 2007)

Massachusetts: VOR to file an Amicus Curiae brief in Fernald case

In August 2007, Federal Judge Joseph Tauro held that Massachusetts may transfer residents from Fernald, subject to a requirement that for each individual, an Individualized Service Plan (ISP) will be developed, state officials will ensure that all ISP-recommended will be available at the new location, and each individual transferred will receive "equal or better" community-based services.

"An essential function of the ISP process is to give residents and guardians a voice in important decisions," Judge Tauro wrote. "Administering the process under the global declaration that Fernald will be closed, however, eviscerates this opportunity for fully informed individualized oversight," he added, relating to the state's long-held plan to close Fernald.

On September 12, 2007, the State announced its plans to appeal the August decision. VOR, in support of the plaintiffs (Fernald residents) and their families, will participate as Amicus Curiae ("friend of the court"). *The case is Ricci v. Okin.*

Massachusetts: Court mulls arguments on transfers

At the end of a day long trial, U.S. District Judge Joseph Tauro said he would issue a ruling soon and may ask the U.S. Attorney's office to investigate whether a 91-year-old mentally retarded woman was moved against her will from the Walter E. Fernald Developmental Center to a group home in Bedford.

The 91-year-old woman, who was referred to in court as "A.T." lived at Fernald for some 50 years before she was moved on Feb. 13.

Witnesses included Linda Curran, who said that she was told by her bosses at Arc of Greater Boston of the longtime Fernald residents, "We gotta move them out," a charge Terri Angelone, CEO of The Arc of Greater Boston denied in her testimony.

Beryl Cohen, an attorney for the Fernald League - a group looking to keep Fernald open - asked the judge to broaden the federal prosecutor's investigation. He

asked that the scope include other transfers out of Fernald completed by the Arc of Greater Boston - a corporate guardian - which were approved by the state.

Yesterday's hearing was called primarily to consider a motion filed last week by the Fernald League, which asked Tauro to bar the transfer of any more residents from the facility until an appeals decision was rendered in the case.

Tauro quickly turned down that request, and said stopping the transfer of residents was not the intention of his order last year, nor was trying to block the state from closing the facility. "My concern is that people who are there and want to stay there, get an opportunity to stay there," Tauro said. (Source: *The Daily News Tribune*, Feb. 26, 2008)

Connecticut: Family sues group home agency following resident's death

The family of a 24-year-old autistic man sued his group home after he drowned. The lawsuit, filed in October 2007, alleges that Community Residences, Inc., a non-profit community provider, failed to adequately protect the man and ensure his safety. The lawsuit contends that Community Residences, which operates 35 group homes for about 500 residents throughout Connecticut, violated several state policies by failing to supervise the man while he was near water and failing to train its employees in aquatic safety, among other allegations.

(Source: *Hartford Courant*, Oct. 11, 2007).

New Jersey: State health plan must cover autism

The New Jersey Supreme Court upheld an appeals court ruling September 12, 2007 to order the state's health insurance plan to cover autism services such as speech therapy, occupational therapy, and applied behavioral analysis/verbal behavior therapy for children of state government workers. *The case is Micheletti v. State Health Benefits.*

Senate & House bills to provide temporary Medicaid fiscal relief

After a failed effort to amend the Economic Stimulus law, on January 31, 2008, Senator Rockefeller (D-WV), Chairman of the Senate Finance Committee's Health Subcommittee introduced S. 2586, the State Fiscal Relief Act of 2008.

If passed, S. 2586 will provide an additional \$12 billion to states through a temporary increase in the federal Medicaid match through 2009. In the House, H.R. 5268, introduced by Rep. Pallone (D-NJ), Chairman of the House Energy and Commerce Committee's Health Subcommittee, also proposes a temporary increase in federal Medicaid matching funds for states.

**BE A SPONSOR.
FIND A SPONSOR**

VOR's Annual Meeting and Washington Initiative is our pinnacle event. Help be a part of its success. **Be a sponsor, find a sponsor.**

Full details, including sponsorship categories are available on VOR's website at: <http://vor.net/2008Sponsorship.htm>.

See last year's sponsors at <http://vor.net/2007sponsors.htm>

THANK YOU!!

**California:
Abuse registry bill reintroduced**

Assemblymember Noreen Evans (D-Santa Rosa), Chair of the Assembly Democratic Caucus, reintroduced legislation to protect the developmentally disabled from abusive caregivers by creating a registry to track them and prevent them from further employment as a caregiver. The bill also requires employers to consult the registry prior to hiring a caregiver, prohibits the hiring of any caregiver listed on the registry, and requires employers of caregivers report instances of abuse to the department for inclusion on the registry.

The first two points -- requiring employers to consult the registry and not hire listed caregivers -- were added to AB 1983 in order to respond to the Governor's veto message of AB 1192, a substantively similar bill authored by Evans last year which passed the Legislature unanimously.

Forty-four percent of abusers make contact with their victims as unlicensed, direct care workers. If caught, investigated, and/or fired, many abusers move on to another agency because they can. Without knowledge of a caregiver's past, employers continue to hire abusive caregivers (Source: *California Political Desk*, February 15, 2008).

**Missouri: New hope
for community oversight**

Missouri State Senator Tim Green and State Representative Gina Walsh have introduced legislation that would, among other things, require that community providers are subject to the same oversight and employee training requirements as habilitation centers (the state's ICFs/MR). In addition, employees convicted of abuse and neglect are to be terminated and no new placements will be made to programs out of compliance (Source: *Missouri VOR Newsletter*, February 15, 2008).

**New Jersey: Housing
waiting list exceeds 8,000**

A state law enacted more than a decade ago promised a group home or apartment for waiting disabled adults. With careful planning and steady investments, the law said, the waiting list of 4,700 people could be eliminated by 2008. Without it, the list would escalate to a staggering 7,500 people.

As of January -- the month the list was to have been eliminated -- there were more than 8,000 people waiting for housing assistance, according to budget records and state Department of Human Services statistics. The list surpassed even the early dire predictions in part because no money was spent on

***"We know the score.
New Jersey is going
through tough times."***

Tom Baffuto, The Arc's executive director housing for disabled people for five of the past 10 years.

The Arc of New Jersey, a family advocacy group, is trying to attract political and financial support to reduce the waiting list but has been unable to gain any traction as most state lawmakers are focused on a looming budget deficit and Gov. Jon Corzine's plan to pay down the state's debt by raising highway tolls.

"We know the score. New Jersey is going through tough times," said Tom Baffuto, The Arc's executive director. "We are in a year where we'll be facing draconian budget cuts. But this is the number one priority with our families. We think this is a crisis situation that is only going to get worse."

After visiting families at home and witnessing "firsthand the profound commitment so many families make to caring for a relative," state Public Advocate Ronald Chen sent a letter to Corzine in December backing The Arc's proposal.

"This is a very real crisis and it must be addressed this fiscal year and every year thereafter until it is resolved," Chen's letter states.

Lilo Stainton, Corzine's spokeswoman, stressed the budgets are tight. "It's too early to comment on specifics for the upcoming budget, but Governor Corzine has made clear that it will include deep and painful -- but necessary -- spending cuts," she said.

The current state budget does include a modest proposal from Corzine that commits \$2.8 million to move about 28 people off the list this year.

There are 7,400 people with developmental disabilities living in subsidized community housing in New Jersey, according to the state budget. Every year, 900 more people are added to the waiting list by their parents, and 300 people move to the top of the list because their parents or caregivers die.

On the eve of budget negotiations for the coming budget year, which begins July 1, The Arc is asking lawmakers to support the "10 Percent Solution."

Of the 8,000 people on the list, half are considered "urgent" placements because their parents are 55 or older or they suffer from a chronic physical or psychiatric disease. Moving 10 percent of them off the urgent portion of the list each year would cost the state about \$15 million, which would be matched by the federal government.

The Department of Human Services would like to tackle the waiting list, but instead it is grappling with "a worsening fiscal picture that has us all reconsidering our priorities," Assistant Commissioner Kenneth Ritchey said.

The Division of Developmental Disabilities' \$1.4 billion budget is also under pressure from the hundreds of people living in state institutions who have sued the state to live in less-restrictive community housing. Most group homes and apartments for disabled people are 98 percent full, Ritchey said.

(Source: *The Star-Ledger*, Feb. 10, 2008)

VOR

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Development--VACANT

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VOR Calendar Events

VOR 2008 Annual Meeting and Initiative:

June 13 - 19, 2008 in
Washington, D.C.

An event
to commemorate VOR's
25th Anniversary will be
held on June 14.
**See pages 10 -11 for
more event information
and event registration
form.**

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:
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**Washington State:
VOR approved as Amicus;
Summary Judgment denied**

With good results, VOR's participation as Amicus Curiae began as quickly as it ended in Lamb v. Washington. In this case, state defendants sought to have the case dismissed arguing that state officials were immune from suit under the state's Abuse of Vulnerable Adults Act (AVAA). Plaintiffs are four former residents of Fircrest Habilitation Center, a state operated ICF/MR, who allege that their move has caused them to suffer "abuse" or "neglect" as those terms are defined in the AVAA.

VOR request to participate as Amicus Curiae was approved the same day the court ruled against the state. In support of the plaintiffs, VOR, through its pro bono attorney Mike Rato, argued, in part, "VOR respectfully requests the opportunity to rebut the defendants' narrow interpretation of the AVAA . . . VOR believes this that this issue – apparently one of first impression – is a cornerstone of the Act, and that acceptance of the defendant's position would seriously undermine the goal of protecting the developmentally disabled from abuse." On February 25, 2008, the Court agreed, granting VOR's request to participate as Amicus and rejecting the State's AVAA immunity arguments.

**Serving a group often neglected
Pennsylvania: Dental clinic
for clients with disabilities opens
Connecticut: clinic planned**

Because of the access problems, mentally retarded people often have serious dental problems. Caregivers face long waits for appointments for disabled people who may not understand how to brush properly and may take medicines that accelerate tooth decay.

There's growing evidence that good dental and physical health go together. Plus, rotting teeth, and the pain that goes with them, can lead to behavior problems, especially in people who can't communicate well.

But, finding dentists willing to accept disabled clients is difficult. Advocates say Medicaid needs to pay dentists more, and dentists need more training in working with people with disabilities. Many states have stopped covering routine dental care for adults, and where it is covered, the rates paid to dentists who provide care are usually lower than those paid by private insurers.

Dental options for this population, however, are expanding in Pennsylvania and Connecticut. *In Pennsylvania, Elwyn, a nonprofit provider of services for people with mental retardation and other disabilities, has opened its second dental clinic for people with disabilities in Philadelphia and is expected to serve 1,800 patients.* Its first clinic, in Media, PA, currently serves 1,400 people.

In Connecticut, TEAM Inc. and two service agencies are also planning to open a 6-seat dental clinic for children with disabilities, with additional space for intensive-out patient services. The agencies already have a smaller clinic; the expansion will allow the agencies to serve 70 more chil-

dren. In addition, the Connecticut Foundation for Dental Outreach recently introduced the "Mission of Mercy" – a large scale, multi-chair dental clinic that travels around the state to serve anyone without dental insurance and in low income situations (Sources: *Philadelphia Inquirer*, September 9, 2007; and *Connecticut Post*, December 17, 2007).

**Virginia: Legislation
to protect vulnerable adults introduced**

State legislation has been introduced to create a Adult Fatality Review Team. HB 251 proposes a process whereby a team will review suspicious deaths of incapacitated older adults subject to Adult Protective Services investigation and in other circumstances. It is expected that the reviews will

help Virginia create evidenced-based approaches to better protecting against neglect and abuse of vulnerable adults such as those with Alzheimer's or a related dementia. (Source: NCA Alzheimer's Association, February 12, 2008).

**Texas: Legislative panel
to study state facilities**

House Speaker Tom Craddick created a special committee recently to monitor state institutions for people with disabilities. The panel is charged with finding ways to improve the quality of care for people with the most severe disabilities in the state – residents of state facilities who require round-the-clock assistance. The panel will also review the lengthy interest lists for people who want care at home or in community group homes, for which some wait up to a decade. More than 100,000 Texans are waiting for such services.

The committee, which has investigative power, must report back to the Legislature with recommendations by December 200

Members will hold several hearings across the state and will probably suggest legislation. (Source: *Dallas Morning News*, January 16, 2008)

Medicaid recipients are increasingly likely to live with parents or other relatives

A new study shows that the number of people with mental retardation receiving Medicaid Home and Community-Based Services (HCBS) while living with family members is an estimated 224,264 (as of June 30, 2006), 17 times higher than in June 1999. A notable policy trend that corresponds with this increased reliance on family-based living is the growth of Medicaid Support Waiver programs. (Source: Charlie Lakin, et al., October 2007). Related statistics indicate that an estimated 25% of individuals with developmental disabilities who live with family caregivers, live with caregivers who are at least 60 years old; an additional 35% live with middle-age caregivers (State of the States, 2005).

Maryland: Governor calls for Rosewood's closure

Rosewood Center in Owings Mills, Md., will be shut down once all of the residents are relocated, which is expected to take 18 months, Gov. Martin O'Malley's office said in a January announcement. Families, however, are challenging the closure, saying that recent reports of abuse and neglect at the center are exaggerated by those who want it closed. Harry Yost, whose son is a Rosewood resident, says the care of his son has been consistently good, and even better in recent years. Families question the wisdom eliminating services when more than 16,000 people are waiting for services; more than half in a "crisis category" (according to the Maryland DD Council).

Illinois and California: Legislation introduced in support of Community Resource Centers

California State Senator Patricia Wiggins recently introduced SB 1183, a bill to establish a "Center of Excellence Outpatient Clinic" at Sonoma Developmental Center, a state operated facility.

"As we face the dual challenges of addressing the health care needs of all Californians, while finding solutions to our budget problems, we should look for ways to make our existing health care resources and

strained budget dollars work more efficiently," wrote Senator Wiggins in a letter about the bill.

Noting that one area needing focus is the provision of medical, dental, and ancillary care to people with developmental disabilities living in the communities, she noted that, "we under-utilize state Developmental Centers' specialized medical and dental resources." SB 1183, if passed, will make these resources available to a wider population of disabled Californians who choose to live in other communities

"My bill will allow disabled people to have these needs met by experienced professionals who specialize in this treatment area currently practicing at Sonoma Developmental Center."

In Illinois, similar legislation has been introduced by state Senator Maggie Crotty (SB 1897) and state Representative Al Riley (HB 4334). This legislation, if passed, will require that Illinois' Department of Human Services operate Community Resource Centers at each of its 9 State-operated developmental centers. The purpose is "to improve services delivered in the community by providing the services of the skilled State workforce to individuals residing in community settings when individuals need those services."

Research finds new evidence about autism

Researchers at the University of California Davis have found 11 genes, all governing "natural killer" immune cells, that are more active in autistic children than in other youngsters. The study bolsters theories that some sort of infectious agent, early in life or even in the womb, might play a role in autism (*Hartford Courant*, January 26, 2008).

Researchers associated with the Autism Consortium, a nonprofit research group in Boston, found strong evidence that a genetic alteration could cause autism, after conducting the most comprehensive DNA scan every performed of families with autistic children. The analysis identified a specific section of DNA where some developmental problems could originate (*New York Times*, January 10, 2008).

More research news

Australian researchers studied the X chromosome of more than 500 families diagnosed with various forms of mental retardation and discovered that certain duplicated genes produced excess protein leading to mental retardation (*AAIDD F.Y.I.*, January 2008).



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VOR 2008 Annual Meeting and Washington Initiative June 13 -17, 2008

JOIN VOICES AND MAKE A DIFFERENCE! PLEASE JOIN US!

[All VOR meetings will take place at the Holiday Inn on the Hill, which will be renamed
The Liaison on Capitol Hill (an Affinia hotel) as of April 1, 2008.
Same location as the past many years: 415 New Jersey Ave., NW, Washington, D.C.]

Friday, June 13, 2008

1 – 3 pm

VOR Annual Board Meeting – VOR members welcome to observe

Friday June 13, 2008

6 – 8 pm

Reports from the States

Participate in reports on news from your state. This more casual session, moderated by VOR Board Members, will be a time for sharing and participating. Appetizers and beverages will be provided.

VOR 2008 ANNUAL MEETING

Network. Learn. Grow. Advocate.

Saturday June 14, 2008

9 am – 4 pm

Annual Meeting

Speakers/Presentations:

- A) **Panel discussion on the Individual Planning Process (IPP):** Brenda Lowry, provider of ICF/MR and nursing level services for people with MR/DD will moderate a panel discussion to focus on the legal (regulatory) requirements regarding the annual IPP process, and how families can be effective advocates during this process. Panelists are Dianne Smith, CMS Technical Director and Team Leader for ICFs/MR; Robin Sims, VOR's First Vice President; and Kathleen Miller, a social worker for Sonoma Developmental Center, where her son is also a resident;
- B) **Federal Disability Policy and Legislative Advocacy, featuring: Pilar Faló, Legislative Counsel to Rep. Barney Frank on "H.R. 3995 legislative update and advocacy"; and a **Federal Disability Policy Expert** from Capitol Hill (tentatively confirmed); and**
- C) **Coalition Building** by Sonya Mawhorter, Executive Director, Ohio League for the Mentally Retarded, a VOR state affiliate.

Saturday June 14, 2008

6:00 pm

VOR's 25th Anniversary Celebration!

The Monocle Restaurant

VOR turns 25 in 2008! Join other VOR members in celebration of this advocacy milestone. VOR will host a reception and dinner at the historic Monocle. Located just off Capitol Hill (Senate side), The Monocle, featuring American Cuisine, was founded in 1960 and remains a favorite for Members of Congress, staff and lobbyists. Full details will be provided to Annual Meeting/Initiative attendees.

Sunday, June 15, 2008

3 – 7 pm

Initiative Briefing

Learn what to do, what to say, and receive folders for distribution to Congress. Complete instructions will be provided and you will learn from experienced attendees. A Keynote Speaker from Capitol Hill will be arranged. Issues will include H.R. 3995 and (we anticipate) the DD Act Reauthorization.

Begins Monday, June 16, 2008

The Washington Initiative

If possible, please plan to spend at least full days on Monday and Tuesday visiting as many Senators and Representatives as possible. The more workers, the lighter the burden.

NEW!

Monday, June 16, 2008

5 - 7 pm

2nd Annual Capitol Hill Reception

Congressional Sponsors and location to be announced

Relax and network with VOR members, Congressional Members and their staff, after your busy day on Capitol Hill.

Monday, June 16, 2008

7:30 pm

Tuesday, June 17, 2008

6:30 - 8 pm

Informal De-briefing

Reports by state spokespersons (identified in advance of the meeting) regarding Congressional visits.

HOTEL INFORMATION

Holiday Inn on the Hill

415 New Jersey Ave., N.W. Washington, D.C. 20001

Reservations due by May 12, 2008 (Note: After April 1, the hotel will be called **The Liaison on Capitol Hill**)

202-434-0125 Marcia Hopkins (direct)

866-Affinia (866-233-4642) (toll-free)

Group rate: \$169 for single or double, plus tax, per night. Mention VOR for group rate. **All meetings will be held at the Holiday Inn on the Hill / The Liaison on Capitol Hill (an Affinia hotel).** Take advantage of networking with other VOR members by staying here. Please let us know if you would like to be paired with a roommate, if possible.

TRANSPORTATION INFORMATION

Ground Transportation

Taxi cabs and "Super Shuttle" are available at Reagan International Airport. "Super Shuttle" is \$12 per person from Reagan. At the airport follow signs to "Ground Transportation." Super Shuttle reservations are required only from the hotel to the airport (800-258-3826). Union Train Station is just 3 blocks from the hotel.

For more information please contact Tamie Hopp at 605-399-1624 or Tamie327@hotmail.com

Registration Form

I'll be there! I want to tell Congress how important choice is for people with mental retardation.

Return form to Voice of the Retarded * 836 S. Arlington Heights Rd., #351 * Elk Grove Village, IL 60007

Fax: 847-258-5273 * Tamie327@hotmail.com * Phone: 877-399-4867 (toll free) or 605-399-1624; a 501(c)(3) org.

Mark all that apply:

Name(s) _____

___ \$50 per person for member registration at the Annual Meeting on Saturday, June 14 if paid by 5/31.

<2008 WASH-REG>

Address _____

___ \$60 per person for member registration after 5/31.

<2008 WASH-REG>

City, State, Zip _____

Home Phone _____

___ \$75 per person for non-member registration at the Annual Meeting on Saturday, June 14 includes one-year membership if paid by 5/31. **<2008 WASH-REG>**

Work Phone _____

___ \$85 per person for non-member registration after 5/31. Membership included. **<2008 WASH-REG>**

Email _____

Family/professional org/company (if applicable) _____

___ A donation of \$ _____ is enclosed.

<2008 WASH-DONA>

Charge card: MC Visa Expiration Date _____

___ I/We will attend the Washington Initiative only, and will be able to make Congressional visits through _____ (specify date)

Credit card number _____

Signature _____

VOR Welcomes Tribute Donations

Gifts have been received

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Bert Barnett
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Jack Lewis
Alma J. Myers
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Ryan Slothower
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In Honor of

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George B. Davis
Robin Sims
Daniel Walsworth
Rosalie Wolff

In Celebration of

Sara Geller's 90th Birthday!

Art and Mary Krueding's
50th Wedding Anniversary!

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