

Fall 2007

**NOTICE:**

New VOR address effective Aug.1

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**President's Message**

**VOR's Awareness Initiative: On a mission to be seen and heard**

By Mary McTernan, President



Over a decade ago, the VOR Board of Directors developed an "awareness" program aimed at ensuring that the VOR name became known throughout the disability community, in the halls of Congress, and in the offices of government agencies. We have made remarkable strides in all these areas. However, there remains much to be done!

**We're off to a great start**

**June 2007:** For more than a decade, VOR's **Annual Conference and Washington Initiative** has served to enhance VOR's credibility and visibility among federal policymakers in Congress and the Administration. Each year, including June 2007, VOR's message, in support choice and family/guardian decision-making, is received by every Member of Congress, representatives in several federal agencies, and representatives of national organizations.

**August 2007:** For the very first time, VOR participated in the **National Conference of State Legislatures** convention. I joined more than 9,000 participants and heard from such prominent speakers as Nancy Pelosi, Andrew Card and historian David McCullough. Robin Sims, VOR's first vice president, with the help of long-time VOR member, George Mavridis, coordinated VOR's exhibit. For three days we reached state lawmakers and their staff with information about Medicaid, long-term care for people with MR/DD, and the importance of choice and family input. Decisions about Medicaid and other critical programs serving our family members are made at the state level. Bringing our message to state lawmakers in every state is critical. VOR will participate at the 2008 NCSL conference in New Orleans.

**September 2007:** VOR's Kelly Guesnier, development professional, met with **retired Senator Bob Dole** on VOR's behalf, as well as other influential contacts who may have an interest in VOR's mission and a willingness to lend financial support.

**September 2007:** VOR joined about 20 other organizations at the **Quarterly Constituent**

**Meeting** sponsored by the Office of Disability/U.S. Department of Health and Human Services. These meetings are regularly attended by representatives of various federal agencies and provide VOR an opportunity to provide input on issues impacting people with MR/DD and their families.

**October 2007:** As VOR's president, I will be the speaker at the "**DD Residential Services Town Hall Meeting**," in Boston, Massachusetts. The Town Hall Meeting is being sponsored by the American Health Care Association.

**October 2007:** VOR will join forces with Parents of Autistic Children (POAC), and co-host a "**Golf Outing for Children and Adults with Autism and Other Developmental Disabilities**." Held at the prestigious Bamm Hollow Country Club in Lincroft, New Jersey, proceeds from the Golf Outing will support equally the good works of VOR and POAC. The event provides a fun way to raise awareness about our organizations and the people for whom we advocate. For more information on how to participate and/or support this event, contact Tamie Hopp at 605-399-1624.

**November 2007:** VOR will exhibit again at the 8<sup>th</sup> annual World Congress & Expo on Disabilities in Washington, D.C. ([www.wcdexpo.com](http://www.wcdexpo.com)). WCD will be attended by 5,000 people with disabilities, their families, caregivers, and the professionals who serve them.

**Let us know of any awareness opportunities**

VOR would welcome learning from you about any opportunities to make more people aware of VOR, our activities and Mission. We especially welcome the opportunity to present or otherwise share information at your family/advocacy association meetings.

If you would like to contribute to VOR's Awareness Initiative, or just support VOR's overall good work, contributions are always appreciated. Thank you!

**Office Update**

The office transition, as reported in the last newsletter, has gone very, very smoothly. Address changes are again published on page 11. Thanks to all of you who have communicated your support for these positive, growth-oriented changes!

# Get It!!

## Guardianship

So many of our members have profoundly disabled adult children, but figure if they are parents, they are okay.

**But**, no matter how cognitively disabled an individual, when they turn 18, they are presumed to be "competent." The need for a guardian has to be approved by a court.

# Do it!!

## Estate Planning

*"The biggest mistake families make is to put off estate planning or to use standard strategies that could actually put a special-needs child at risk...*

*Parents and well-meaning relatives who give a disabled child money -- either now or in their wills -- could make the child ineligible for some benefits."*

Adrienne Arkontaky

# Planning for your disabled child

By Kimberly Lankford

© Kiplinger's Personal Finance magazine, Aug. '07  
(visit <https://www.kiplinger.com/orders/magazine/> for subscription information)

Matthew Troncone spent the first years of his daughter Brittany's life in doctors' offices and hospital waiting rooms. From birth, Brittany showed signs of developmental delay, but it took many consultations and months of testing to determine the cause.

"My main focus was making sure I understood everything," says Matthew. "I said I'd worry about the finances later."

Children with special needs require so much immediate attention, including managing their health care and navigating the social-services maze, that parents often find it hard to make time to plan for their finances. And many parents with financial resources assume that they won't qualify for assistance to help care for a disabled child, says Gordon Homes, a certified financial planner with MetLife's division of estate planning for special kids.

But if you have a special-needs child, you are entitled to benefits and programs that can help relieve the crushing costs of your child's care. And long-term financial planning is essential to make sure that your child receives the benefits you've worked so hard to secure, even when you can no longer care for him or her yourself.

### Get aid to which you're entitled.

After Brittany's problem was finally diagnosed, Matthew applied for Medicaid. He earns too much to qualify himself. But Brittany's condition makes her eligible for coverage. Matthew's health insurance provides primary benefits; Medicaid fills the gaps.

Even with good health coverage, Matthew had to pay about 15% of Brittany's medical costs himself before Medicaid kicked in. (Now, almost 100% of Brittany's health care is covered.) But he was able to deduct non-reimbursed medical expenses on his tax return. You are entitled to write off such medical costs after they exceed 7.5% of your adjusted gross income. With co-payments and out-of-pocket costs for tests and travel, the Troncones quickly crossed that threshold.

Schooling for special-needs kids is also subsidized until the ages of 18 -21. Brittany started receiving physical and occupational therapy at age 3 through an early-intervention program in Dutchess County, N.Y., where she and her father live.

When local budgets are strapped, however, families with special-needs kids may need a lawyer or advocate to obtain the best educational program available, says Bernard Krooks, a special-needs attorney in New York City.

### Open a special-needs trust.

When Adrienne Arkontaky counsels families with disabled children to make an estate plan, she speaks from personal experience. Her daughter, Jordan, now 15, was born with cerebral palsy, and Arkontaky went to law school to become a special-needs attorney so she could help other families make the most of their benefits.

*Long-term financial planning is essential to make sure that your child receives the benefits you've worked so hard to secure, even when you can no longer care for him or her yourself.*

The biggest mistake families make, says Arkontaky, is to put off estate planning or to use standard strategies that could actually put a special-needs child at risk. For example, in order to qualify for Medicaid and other benefit programs, special-needs children may not have more than about \$2,000 in their own name. Parents and well-meaning relatives who give a disabled child money -- either now or in their wills -- could make the child ineligible for some benefits, and he or she would need to spend down the money and re-apply. Some parents think they can solve this problem by disinheriting their disabled child and giving the money to a sibling or family member who promises to provide the child's support. But such a solution puts enormous stress on the sibling and still doesn't guarantee that the child's needs will be met.

# The right moves today will ensure that your child's needs will always be met

## Plan for an adult child.

Your child reaches a major milestone when he or she turns 18. At that point, children automatically become their own guardians, regardless of their ability to manage their lives. If you don't apply for guardianship, you may not have the legal authority to make medical and other decisions for your child.

Arkontaky recommends starting the application process at least a year and a half before the child turns 18. Even if your child is only moderately disabled and can serve as his or her own guardian, you should have a health-care proxy so you can make medical decisions if your child is unable to.

The source of your child's benefits also changes at age 18, as he or she moves out of special education and into adult services, says Harry Margolis, a special-needs lawyer in Boston. Many school systems allow disabled children to remain in their programs until age 21, but families must track down a new set of benefits after that.

*"We lived below our income and saved like mad. It always helps to have the money — you get better placement in programs. If people don't save, I don't know how they're going to do it." Elis Yokelson*

Your disabled child might qualify for Supplemental Security Income from Social Security, start a job and move out of your home and into group housing (the cost of which may be covered by the state or a nonprofit organization). If your child does get a job, be aware that his or her income could reduce SSI, Medicaid and other benefits.

Amanda Sham of Bala Cynwyd, PA, was born with microcephaly. Now 26, Amanda graduated from a special-education program at her local high school and works as a teacher's aide in a day-care center, a job she loves and looked for herself.

"She needs help in many aspects of daily living," says her father, Bruce. "She can't shop or cook by herself, and she will never drive." Bruce is a financial planner with MassMutual's SpecialCare program, which focuses on planning for families who have children with special needs.

As long as Amanda doesn't earn more than \$900 per month in 2007, she is eligible to receive Social Security disability benefits. Although she actually earns close to \$1,000, she is allowed to subtract expenses, such as the cost of getting to work, which puts her income below the cutoff. She is covered under her parents' health-insurance policy as a permanently disabled adult, and Medicaid supplements the private coverage. The Shams are glad she has dual coverage because her dentist and doctor do not see Medicaid patients.

In addition to her special-needs trust, Amanda has a so-called OBRA '93 trust in which she deposits the money she earns from her job, plus birthday presents and other gifts, so she doesn't cross the asset limit for Medicaid eligibility. She can use the money for anything that benefits her health, welfare or education.

## Plan for yourself.

Bruce Sham and other special-needs planners say that it's easy to spend most of your time and money on your child and neglect your own finances. But you may need to save for college for other children, and you certainly need to prepare for your retirement -- especially because your child with special needs could be dependent on you long after you retire. Long-term-care insurance for yourself is also a good idea -- and it will allow you to preserve your savings for your child's care.

Savings made a huge difference for Elis Yokelson of Sharon, Mass., who is 80 and has two children in their late forties with special . "We lived below our income and saved like mad," says Yokelson, a retired teacher. "It always helps to have the money -- you get better placement in programs," she says. "If people don't save, I don't know how they're going to do it."

## Find help.

If you have a child with special needs, it's important to work with a local lawyer and financial adviser because laws and resources vary from state to state.

Several new organizations make it easier to find special-needs planning experts, many of whom have disabled children themselves and can also help you navigate the benefits system and track down local resources.

**The Special Needs Alliance** is an invitation-only organization of about a hundred lawyers who focus on special-needs planning - [specialneedsalliance.com](http://specialneedsalliance.com).

**Specialneedsanswers.com** provides contact information for members of the Academy of Special Needs Planners. Several financial-service providers now offer special-needs planning: \*MassMutual's SpecialCare program (800-272-2216; [www.massmutual.com/specialcare](http://www.massmutual.com/specialcare)),

\*MetLife's MetDESK (877-638-3375; [www.metlife.com/desk](http://www.metlife.com/desk)) and;

\*Merrill Lynch's division of special-needs financial services (877-456-7526; or go to [www.askmerrill.ml.com](http://www.askmerrill.ml.com) and click on "Advice and Planning," then "Special Needs Network").

## **P&A Reform is Needed**

**Court rules in favor of P&A, against family objections; case to proceed as a class action**

The Court of Appeal for the First Appellate District held that Capitol People First (CPF) v. Department of Developmental Services (DDS) may proceed as a class action on behalf of more than 7,000 individuals who receive services from regional centers and are either living in state or private institutions, or are at risk of institutionalization. Plaintiffs are represented by California Protection and Advocacy (PAI).

### **Background**

CPF v. DDS was filed "to eliminate systemic policies and practices of the state and regional centers resulting in the unnecessary institutionalization of thousands of people with developmental disabilities." In the 1990s a similar PAI lawsuit led to transfer from developmental centers of some 2400 individuals over a 5-year period.

### **Families oppose lawsuit, class certification**

State defendants and interveners (families) opposed class certification, arguing that because everyone's needs are individual, issues over inappropriate institutionalization can only be addressed on an individual, case-by-case basis. They also argued that PAI could not represent the interests of all class members. The appellate court overruled the lower court, which had denied class certification. (Source: PAI (excerpts), Sept. 27, '07).

## **Rep. Barney Frank's "Family Rights" Bill: Good things are worth the wait.**

In the last issue of *The Voice* (Summer 2007), we reported that Rep. Barney Frank plans to revise his "Family Rights" bill. This legislation, as originally drafted, would require that Protection & Advocacy (P&A) notify guardians, and obtain their authorization, before pursuing lawsuits on behalf of family members/wards with mental retardation.

*"This issue is so important, and your help in getting this legislation passed so critical, that VOR will be notifying every VOR member by regular mail, along with an email action alert, immediately upon news of the bill's reintroduction."*

Throughout August 2007, VOR was in communication with legislative counsel, sharing our input with regard to the devastating impact of class action lawsuits on many individuals with severe and profound mental retardation in several states.

As we understand, Rep. Barney Frank is very close to finalizing his revised bill. Although other Congressional obligations have demanded his time, he has consistently pledged his commitment to individuals with mental retardation and their families.

### **Coming Soon! Watch your mailboxes!**

We expect a revised "Family Rights Bill" very, very soon. This issue is so important, and your help in getting this legislation passed so critical, that we will be notifying every VOR member by regular mail, along with an email action alert, immediately upon news of the bill's reintroduction. Updates will also be posted on VOR's website – <http://www.vor.net>.

*Good things are worth waiting for.* Thank you for your patience.

### **VOR calls for no funding increases for DD Act programs**

On October 3, VOR issued a statement to House and Senate appropriators calling for "no funding increases" for state DD Councils or P&A's until Congress has had an opportunity to study the impact of these programs' activities on people with severe and profound mental retardation.

"The DD Act was last reauthorized in 2000. Seven years is a very long time for any federal program to receive funding with virtually no Congressional oversight . . . **Before** approving funding increases, Congress is urged to use this opportunity to study the issues, difficulties and flaws in the DD Act, and implement reform that requires state DD Councils and P&As to represent all disabilities, regardless of severity of need and service setting of choice."

The House of Representatives has passed a bill calling for no increases for P&A, but an increase of \$5 million for state DD Councils (H.R. 3043). The Senate Appropriations Committee supports an increase of \$4 million for P&A and \$5.5 million for DD Councils (S. 1710). The full Senate has yet to act.

### **Senate Finance Committee considers long term care options; VOR submits statement**

On September 25, the Senate Finance Committee heard from state policymakers and advocates regarding the need for expanding community-based long term care options, including consideration of S. 799, the Community Choice Act of 2007.

VOR's Washington Representative, Larry Innis, attended the hearing and VOR issued a statement for the hearing record, stating in part, "Given the diversity of needs and level of disability across the spectrum of the population with mental retardation, coupled with a waiting list exceeding 200,000 people nationally, the need for expanded (not narrowed) service options is clear. . . VOR cannot support a bill [S. 799] that very well could, albeit unintentionally, reduce funds for the most fragile, most needy, and most disabled of our constituency."



# Legislative News

## **50 State Medicaid Benefits: Online database updated to reflect 2006 survey data**

The Kaiser Family Foundation's Commission on Medicaid and the Uninsured issued its latest update (October 2006) of the interactive Medicaid Benefits: Online Database, available at <http://www.kff.org/medicaid/benefits/index.jsp>. Using this tool, Medicaid benefits can be compared across the 50 states, the District of Columbia, and the U.S. Territories, or by specific service. Information about benefits covered, limits, co-payments and reimbursement is available, as is an interactive map, and an expandable list of benefits.

## **State Medicaid spending to increase, survey says**

Medicaid spending will increase by an estimated 5.8% in fiscal year 2008, compared with 6.6% in FY 2007, according to a survey conducted by the National Governors Association (NGA) and the National Association of State Budget Officers (NASBO). All states in the past five years have implemented measures to limit Medicaid spending, "with the majority centered on freezing or reducing provider payments and managing prescription drug costs." (Source: NASDDDS, July 20, 2007; see [www.nasddds.org](http://www.nasddds.org), for subscription information).

## **Iraq spending bill includes delay on Medicaid rule**

The spending bill for the Iraq war, which passed, includes a provision to delay by one year implementation of a Medicaid rule to curtail intergovernmental transfers, a scheme used by some states to maximize federal Medicaid funding.

## **Health care and the presidential campaign**

A website sponsored by the Kaiser Family Foundation includes easy access to health-related resources from the 2008 Presidential campaigns, other organizations, and news outlets. Visit <http://www.health08.org>.

# Legislative News

## **Federal legislation to create Financial Security Accounts for Individuals with Disabilities has growing support**

*National Down Syndrome Society and  
National Down Syndrome Congress  
join growing list of supporters*

June 11, 2007

Washington, DC –The Financial Security Accounts for Individuals with Disabilities Act of 2007, HR 2370, is a bi-partisan proposal to create tax-exempt savings accounts designed for the specific needs of individuals with disabilities.

*FSAID's can be used for  
expenses including education,  
medical/dental care not covered by  
private health insurance and more.*

"The National Down Syndrome Society and the National Down Syndrome Congress understand the special care required to provide for a disabled child's future and the extraordinary expenses their families often have to bare," said the bill's sponsor Congressman Ander Crenshaw (R-FL). "Drawing on their decades of experience, these organizations have decided to join our effort in creating flexible savings accounts that would help families of disabled children afford these expenses and prepare for their child's future. These endorsements represent the growing support the Financial Security Accounts for Individuals with Disabilities Act is receiving and demonstrates the positive impact this bill would have for disabled individuals and their families across the country."

This legislation would create tax exempt Financial Security Accounts for Individuals with Disabilities (FSAID's) that could be used for expenses related to a disabled beneficiary including: education, medical and dental care not covered by private health insurance, community based support services, employment training and support, moving, assistive technology, and, after the age of 18, housing and transportation.

# Fact Sheet

[Rep. Ander Crenshaw  
(R-FL)]

A typical tax-deferred savings plan, such as a "529" college tuition plan, can't help a family with a child who may not go to college or become financially independent.

On the other hand, the need for savings is even greater for a child with a disability because he or she will likely be less able to earn an income, and may require additional spending on medical treatment or adaptive equipment.

Without a clear vision of the future, parents of children with disabilities must choose between turning down the advantages of savings plans or risking a penalty if their child cannot use the funds according to account restrictions.

**H.R. 2370, the Financial Security Accounts for Individuals with Disabilities Act of 2007, will amend the IRS code of 1986 to provide for the establishment of Financial Security Accounts for Individuals with Disabilities (FSAID) for the care of family members with disabilities.**

# Massachusetts victory faces

**Judge bars closing of Fernald – Says residents must be given chance to stay**

**Mass. govt. files appeal in Fernald case**

## Indiana

The Indiana Court of Appeals ruled July 16 that the Family and Social Services Administration (FSSA) broke state law when it granted a no-bid \$95 million contract to Liberty Healthcare to operate the now-closed Fort Wayne Developmental Center. The FSSA “failed to follow the public bidding process as required for Public-Private Agreements,” Judge Patricia A. Riley said in the decision, “We conclude that the trial court abused its discretion in denying appellants’ request for preliminary injunctive relief.” (Source: *Community Services Reporter*, August ‘07; see <http://www.nasddds.org>, for subscription information).

## Texas

Texas lawmakers are considering whether the state should comply with the federal Americans with Disabilities Act (ADA). If passed, Texans with disabilities who believe they have been discriminated against by public agencies would have the right to sue the state under federal law. (Source: *Community Services Reporter*, August 2007; see <http://www.nasddds.org>, for subscription information).

On August 14, a federal judge halted the state's plan to close the Fernald Development Center in Waltham, ruling that the profoundly mentally retarded residents who have lived there for decades must be given the opportunity to stay.

US District Judge Joseph L. Tauro found there has been a "systemic failure" by the state to consider the individual needs of longtime Fernald residents by pushing its plan to close state institutions and transfer residents to community-based group homes or smaller facilities.

In a his ruling, Tauro said he agreed with the results of a court-ordered investigation by US Attorney Michael J. Sullivan, who concluded in March that for some Fernald residents a transfer "could have devastating effects that unravel years of positive, nonabusive behavior."

***"I'm pleased to hear that maybe this is going to come to an end and people can live their lives out in peace..."***

*Marilyn Meagher, parent*

Tauro said his ruling does not mean the state may never close Fernald, which currently houses about 185 residents. "It does mean, however, that the Department of Mental Retardation must carefully assess the needs and wishes of each resident..." he wrote.

The ruling, capping a 35-year legal battle over the state's care for the mentally retarded, was greeted as a victory by some and as a disappointing defeat by others.

"I'm pleased to hear that maybe this is going to come to an end and people can live their lives out in peace that want to stay there," said Marilyn Meagher, president of The Fernald League for the Retarded.

"There are many people who would like to stay at Fernald, and my sister is one," said Meagher, whose 56-year-old sister, Gail, has lived there since she was 4 years old. "It now gives us a choice." (The Boston Globe (© Copyright The New York Times Company))

Massachusetts Secretary of Health and Human Services JudyAnn Bigby, M.D., announced today that the state will appeal Judge Joseph L. Tauro's recent decision in the case of *Ricci v. Okin*, which required the Department of Mental Retardation (DMR) to offer the Fernald Developmental Center as an on-going option for current residents.

The state also announced that, pending the outcome of the appeal, it intends to work toward closing Fernald and will facilitate a transition that prioritizes cooperative individualized planning with each resident. In the meantime, they state that they intend to comply with the current order while it is in effect.

In announcing the appeal, Bigby said, "We understand and respect that people who have lived much of their lives in institutions and their families may wish to continue institution-based services. The Department of Mental Retardation will ensure that these residents will have an opportunity for placement at one of Massachusetts' remaining institutions."

***"The state also announced that, pending the outcome of the appeal, it intends to work toward closing Fernald..."***

*Massachusetts Office of Health and Human Services*

The state's decision is consistent with a national shift away from institutional care in favor of community living. Governor Deval Patrick's administration believes that community living is the best living environment for persons with developmental disabilities.

There are seven institutions for people with mental retardation in New England—six in Massachusetts. (Mass. Office of Health and Human Services, Press Release, 2007).

# opposition

## Both sides weigh-in on ruling

### Pro

The Massachusetts Coalition of Families and Advocates for the Retarded, Inc. (COFAR) support Judge Tauro's ruling. COFAR, a 25-year old statewide organization of family members who care for the some of the most vulnerable people with mental retardation/developmental disabilities in MA, expressed relief and optimism as Judge Tauro reaffirmed the right of such patients and their loved ones to choose settings for treatment, including the Fernald Center.

"This is a clear decision endorsing family choice and a full continuum of care," said COFAR President David Hart. "The judge has told Massachusetts – and probably warned every other state government – that the law does not tolerate the kind of intimidation families faced when Governor Romney announced he was closing all the large facilities, and the Department of Mental Retardation warned families and guardians that they better transfer their loved ones out of Fernald in a hurry -- because those who waited wouldn't get any choice at all." (COFAR)

***"It's going to leave a legacy for this case not any of us want, basically to keep those state institutions open as long as possible." Leo V. Sarkissian***

### Con

Leo V. Sarkissian -- executive director of The Arc of Massachusetts, which advocates for the developmentally disabled -- called the decision disappointing and said it will force the state to spend money to keep Fernald open at a time when there are waiting lists of mentally retarded people who are seeking placement in community-based group homes. "We hope it's going to be appealed," Sarkissian said. "It's going to leave a legacy for this case not any of us want, basically to keep those state institutions open as long as possible." (*Boston Globe*)

## Illinois: Protection & Advocacy efforts to seek resident records in Ligas case thwarted

On August 10, 2007, residents of private facilities in Illinois were handed a victory when the federal court approved a motion to declare invalid ("quash") subpoenas issued by Equip for Equality (Illinois' Protection and Advocacy – P&A) in the Ligas v. Maram case.

***"The Court agreed that the subpoenas were overly broad and thus unenforceable, 'unless Plaintiffs can articulate specific reasons outlining the relevance and need for the breadth of these subpoenas.'"***

In Ligas, P&A has targeted private facilities with more than nine residents, alleging that residents are not given adequate opportunity for community integration. As part of their case, P&A sought the records of 100 "randomly selected" residents from various facilities across the state. The subpoenas requested the residents' complete files, including but not limited to all health care records, individual service plans, psychological, psychiatric, therapies and education plans. For 50 of these residents, the subpoenas also requested access to the individual for the purpose of observing these individuals for a full day.

Nineteen facilities joined in a motion to quash the subpoenas arguing that they were overly broad in that they sought information irrelevant to the suit. Privacy limitations were also raised, citing federal and state law.

The Court agreed that the subpoenas were overly broad and thus unenforceable, "unless Plaintiffs can articulate specific reasons outlining the relevance and need for the breadth of these subpoenas." The court was particularly troubled by the proposed observations of 50 residents, stating "the Court does not understand how the personal observations – even 50 personal observations – of an expert on a given day can provide reliable statistical evidence. Because the Court believes that the experts' observations will be subjective, the Court believes that Plaintiff's expert's personal observations can lead only to very marginal probative evidence, if any at all." (Ligas v. Maram, Opinion & Order, Aug. 10, '07).

## STATE BRIEFS

### Louisiana

Louisiana's Office for Citizens with Developmental Disabilities (OCDD) will receive 17% more funding in 2008 to expand home and community based services waiver opportunities. The State will also dedicate 12% of the state's surplus to further increase waiver opportunities, to include higher reimbursement rates to providers.

The state also approved \$2 pay increases to direct support staff in community and facility programs and funding was approved for the state's Family Opportunity Act that allow qualifying families to purchase insurance through the Medicaid program.

### Kentucky

The Centers for Medicare & Medicaid Services (CMS) approved a new Medicaid waiver to allow Kentucky to provide nonresidential community services to 3,000 individuals MR/DD on the waiting list, and up to 10,000 people. The waiver fulfills a portion of the 2006 settlement agreement between the state and Protection and Advocacy regarding the provision of community-based services.

**VOR's Contribution:** In Ricci (MA), the court adopted our counsel's Olmstead perspective; and in Ligas (IL), VOR arranged for legal counsel for family interveners.

## STATE BRIEFS

### New Hampshire

Gov. John Lynch signed a law July 17 aimed at eliminating over the next three years the waiting list for services for people with DD and acquired brain disorders.

**Senate Bill 138** increases the availability of community-based services for these New Hampshire citizens and helps ensure agencies will have sufficient staff. (Source: *Community Services Reporter*, August 2007; see <http://www.nasdds.org>, for subscription information).

### Alabama

Some lawmakers are considering a measure that would add a 2-cent sales tax on soda pop to raise money to provide services for Alabamans with disabilities currently on waiting lists.

(Source: *Community Services Reporter*, August 2007; see <http://www.nasdds.org>, for subscription information).

### AL, MA, IN, CT, NH, MO, SD

Alabama and Massachusetts are considering "respectful language" laws. **Indiana, Connecticut and New Hampshire, passed laws** relating to use of respectful language in state government and laws. Missouri and South Dakota considered such laws; they did not pass. (Source: *Community Services Reporter*, August 2007; see <http://www.nasdds.org>, for subscription information).

## Guardian fights for right to represent son

**A Missouri father has appealed his son's case to the Eight Circuit Court of Appeals, arguing that he has a right to serve as his son's "pro se" attorney.**

Stephen Saxton, the plaintiff in *Saxton v. Gilbert* (District Manager, Social Security Administration), has profound mental retardation, is nonverbal, and physically disabled. Stephen's father, Richard Saxton, is Stephen's guardian and primary caregiver. In lower court proceedings, the plaintiff has alleged that Missouri illegally denied him certain Medicaid benefits.

In particular, plaintiff is seeking court approval to allow him to pay back a certain portion of his Social Security Disability Insurance (SSDI) (\$15), which at his current level renders him ineligible for Medicaid's Qualified Medicare Beneficiary (QMB) benefits.

Medicaid QMB benefit allows certain low-income disabled or elderly people receive Medicaid for the purpose of paying their Medicare premium. Plaintiff has argued that "in 2006 the federal government improperly manipulated the values of cost of living increases and the Federal Poverty Level, thereby eliminating Medicaid QMB coverage for many recipients, which the Medicaid Statute refers to as 'categorically needy'" (Plaintiff's Second Consolidated and Amended Motion, March 29, 2007). Plaintiff points to a provision in Social Security law which requires social security beneficiaries "take all necessary steps to obtain" the

benefits to which they are entitled, "unless they can show good cause for not doing so." 42 C.F.R. §435.608(a).

Throughout these proceedings, Richard Saxton, Stephen's father, has prepared the filings in his son's case, with only minimal legal support. His efforts to retain an attorney have been unsuccessful, with the attorneys he approached denying any knowledge of the complexities of the specific Medicaid issues at the heart of this case. A motion to the District Court to appoint Stephen an attorney was also denied. Consequently, the District Court dismissed the case, finding that a guardian cannot act as his son's attorney.

*"By denying Plaintiff's guardian the opportunity to proceed on behalf of Plaintiff in this case the District Court has in essence denied Plaintiff his constitutional right of representing himself. Plaintiff's fundamental and legal rights can be advanced only by and through the efforts of his guardian, conservator and primary caregiver."* *Saxton v. Gilbert*, pro se appellate brief, Sept. 13, 2007

On appeal, Richard is hopeful that the recent United Supreme Court ruling in *Winkelman*, which found it appropriate for parents to represent their minor children in cases involving special education (IDEA) disputes, will weigh favorably in the Eight Circuit's analysis of his appeal, which argues that guardians should be permitted to represent their wards in court.

### Montana: Senate approves benefit funding for direct-support workers

Governor Brian Schweitzer signed Senate Bill 206 into law May 16 to increase the state's Medicaid payments to agencies effective January 2009 so that direct-support workers can obtain health insurance. A number of the 500-700 workers, who would receive the benefit, provide services to Montanans with developmental disabilities. The new law requires the Department of Public Health and Human Services to conduct a study to determine the feasibility, impact, and cost of providing Medicaid-

provider (employer) sponsored health care for personal-care attendants and direct care workers, providing that the providers receive additional Medicaid payments for the purpose of providing health insurance.

Another approved measure provides funds to enable all direct care support workers statewide to earn a minimum of \$8.50 an hour – at least matching the state's minimum wage. (Source: *Community Services Reporter*, August 2007; see <http://www.nasdds.org>, for subscription information).



## Pennsylvania – budget boosts DD services

Pennsylvania Governor Edward G. Rendell approved legislation July 18 to implement the 2007-2008 budget. The new budget includes:

- Sufficient funding for services for more than 3,400 Pennsylvanians with mental retardation – the largest increase in nearly a decade. This initiative will provide support to 68% of individuals on the non-emergency waiting list for residential services, as well as 100% of those waiting for non-residential service.

- Funding to serve adults with autism through the Autism Capitated Assistance program – an innovative, prepaid inpatient health plan. This budget also provides for new statewide training and technical assistance, information outreach, assessment procedures, and program monitoring to continue improving services for adults with autism, and;

- Sufficient funding for a 3% cost-of-living increase for direct care staff who provide vital home-and community-based services.

(Source: *Community Services Reporter*, August 2007; see <http://www.nasddd.org>, for subscription information).

## Arizona—new law responds to Prop 202 re: sheltered workshop pay

Under a new law, employers or entities in Arizona are exempt from paying minimum wage if they can prove “that the act or omission was in good faith, conformed with and relied on an administrative regulation, order, ruling, approval, or interpretation, administrative practice or enforcement policy issued by the Industrial Commission of Arizona.”

The law was passed in response to Proposition 202, which Arizona voters passed last November. Prop. 202 raised the state’s minimum wage to \$6.75 per hour, with no exception, including sheltered workshop employees. Typically, sheltered workshops are used as training ground for persons with disabilities, to prepare them for competitive employment, where possible.

Many sheltered workshops were forced to close their doors in light of Proposition 202 because they could not afford paying their workers with developmental disabilities minimum wage. (Source: *Community Services Reporter*, August 2007; see <http://www.nasddd.org>, for subscription information).

## California budget update

SB 77, the fiscal year 2007-08 state budget bill, was approved by the legislature on August 21, after a 52-day standoff that featured 15 members of the Senate blocking passage in an effort to reduce state spending in the face of a predicted \$5 billion “structural” deficit that may force further reductions next year – especially in health and human services, one of the few areas of state spending where lawmakers have some discretion (*See, The Voice, Summer 2007, State News*).

In an effort to resolve the budget issue, the governor promised to make \$700 Million in budget cuts before signing it. The governor can use his line item (blue pencil) veto power only in areas of the budget that do not also require supporting changes in state law.

The budget contains ‘cost containment’ measures (which can reduce eligibility for services or reduce service utilization) as passed in prior budgets for regional center-funded community-based services, and requires the Department of Developmental Services (DDS) to deliver a plan to reduce regional center spending to the legislature by October 1, 2007.

A trailer bill, attached to the budget bill, requires that the DDS continue operating the Agnews Outpatient Clinic, which provides specialized health and dental services, after the closure of Agnews and until DDS is no longer responsible for the Agnews property. A pending bill, SB 725, requires essentially the same thing (Source: CAR Memo, Aug. 23, ‘07).

### Other California Bills of Interest

**AB 1192** aims to protect citizens with developmental disabilities by creating a registry tracking abusers who are seeking employment working with DD individuals.

**AB 1184**, if passed, will require DDS to establish an Agnews Developmental Center Transition Advisory Task Force consisting of current and former residents of Agnews and their families for the purpose of monitoring community placements. The task force would make recommendations to the department, regional center, and the legislature.

**AB 1402**, if passed, will grant a consumer, parent or guardian the right to make an audio tape recording of an individual program plan meeting and require regional centers and vendors to provide appeal procedure information on their respective websites.

(Source: Fairview Families and Friends Newsletter, August 2007).

## STATE BRIEFS

### FLORIDA

State Senate Majority Leader Mike Fasano has reintroduced legislation aimed at ensuring that proposals to downsize or close state facilities be the subject of comprehensive public hearings, following notice to families. SB 232 also gives the Florida Cabinet authority to approve (or reject) a closure proposal, after full consideration of the health and welfare of the individuals impacted, and the cost to the state.

### Washington

The Washington State Dept. of Social and Health Services has approved temporary “instructional space” for some of the 18 children admitted to Fircrest Habilitation Center over the past several months. Fircrest is a state operated facility for persons with MR.

These children first moved to Fircrest because their natural supports and community programs were unable to serve them.

Fircrest, in partnership with the Shoreline School District, is helping to provide these children with an appropriate education, as required by federal law. Fircrest is also carrying out its duty to serve as a “safety net” when natural supports and providers cannot meet the needs of those with severe MR/DD.

## 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, visit [www.vor.net](http://www.vor.net) or [www.poac.net](http://www.poac.net).

#### Nov. 15-17

VOR exhibit at the World Congress & Expo on Disabilities, Washington, D.C. See [www.wcdexpo.com](http://www.wcdexpo.com) for more information.

Join Us!  
**June 13-18, 2008**

VOR's 2008 Annual

Meeting and Initiative in Washington, D.C.

#### June 2008: VOR's 25<sup>th</sup> 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.

## Grieving: Parents, siblings of disabled kids suffer from loss

**Parents** of a severely disabled child often feel the same sense of unresolved grief as parents of missing children or people who lose a loved one to the cloudy depths of Alzheimer's, according to a new study done at Brigham Young University.

In the journal *Family Relations*, professor Susanne Olsen Roper and doctoral candidate Jeffrey b. Jackson show that these families face "ambiguous loss."

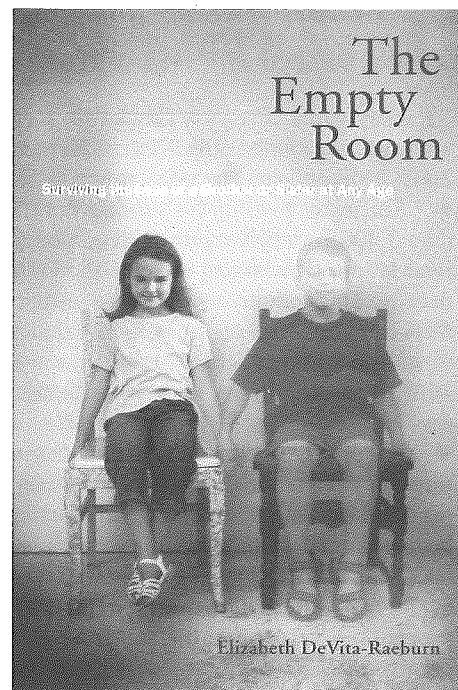
The BYU study looked at 20 families in which a profoundly disabled child was placed in specialized care outside the home. Of the 36 parents who participated, 75 percent said they felt a sense of loss while raising a disabled child at home as the reality sunk in that the child was not the person they envisioned during pregnancy. Once a child was placed in out-of-home care, 65 percent of parents said the child was always on their mind (Source: *Salt Lake Tribune*, August 2007).

### Recommended Reading: *The Empty Room*

**Siblings** of persons with profound mental retardation may find that they can relate to the experiences detailed in the book, *The Empty Room* by Elizabeth DeVita-Raeburn.

*The Empty Room* relates the experiences of siblings following the death of their brothers or sisters. The author explains that typically the focus of sympathy is directed at the parents' loss, to the neglect of the sibling who is also grieving. Further, siblings feel an obligation to "be strong" for their parents and in some cases try to fill the shoes of the deceased sibling. This creates a scenario where siblings "bury" their grief. Author De-Vita-Raeburn describes sibling loss as "ambiguous," and the failure to fully grieve and reach closure often results in emotional problems later in life.

"Jane Anthony, former VOR first vice president, recommended this book, suggesting that siblings of disabled family members often experience a similar loss," said Tamie Hopp, VOR's Director of Government Relations and Advocacy said. "Either the sibling demands the parents' time, they are not the playmate and 'soul mate' envisioned, and when placed out of the home, there is the 'empty room.'"



#### From Simon & Schuster Publishers

Ted is Elizabeth DeVita-Raeburn's older brother, best friend, and the "ringmaster of her days." On a September morning when she is six, she wakes up and Ted is gone. Her parents explain that he went to the hospital for a while. "A while" turns out to be eight years in a plastic bubble, where he dies of a rare autoimmune disease at age seventeen. *The Empty Room* is DeVita-Raeburn's unflinching, often haunting recollection of life with Ted, woven into a larger exploration of the enormous -- and often unacknowledged -- impact of a sister's or brother's death on remaining siblings.

With an inspired blend of life experience, journalistic acumen, and research training, DeVita-Raeburn draws on interviews of more than two hundred survivors to render a powerful portrait of the range of conditions and emotions, from withdrawal to guilt to rage, that attend such loss. Finding little in professional literature, she realizes that those who suffer are the experts. And in the end, it is DeVita-Raeburn and her experts who present a larger, more complex understanding of the sibling bond, the lifelong impact of the severing of that bond, and the tools needed to heal and move forward.

*The Empty Room* is a fascinating literary hybrid in which Elizabeth DeVita-Raeburn seamlessly fuses deeply affecting remembrance with a pragmatic, lucidly written exploration of the healing journey.

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### Correction

The Summer 2007 issue of *The Voice* incorrectly referred to Marty Pratt's wife's name as Evelyn. Marty's wife was Ellen. Our sincere apologies for this error.

### Toll free

877-399-4VOR

### Website

<http://www.vor.net>

### VOR Weekly E-Mail Update

[http://www.vor.net/  
current.htm](http://www.vor.net/current.htm)

**(to receive the update  
directly, contact  
[Tamie327@hotmail.com](mailto:Tamie327@hotmail.com))**

## **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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on this form.  
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If the minimum dues requirement poses a financial difficulty, please contact our office in confidence. It is in our best interest that you receive VOR's information, so please call if \$25 per year poses a financial hardship.

**Oct07NL**

# VOR Welcomes Tribute Donations

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## In Celebration of

The 50<sup>th</sup> Wedding Anniversary of  
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