



**President Robin Sims represents  
VOR on Geraldo**

**pg 4**

**Plan to attend Annual Meeting pg 10-11**



# When given a "Recipe for Disaster," advocates must find a way to make cake

## The President's Message

By Robin Sims

## The Recipe

ONE written state directive that requires planning teams to conclude that every facility resident is "eligible for community placement unless they represent a serious danger to others" (emphasis in the original).

**MARINATE** the state directive for about eight years. The result will be a finding that there are 2,400 facility residents who are appropriate for community placement (Caution: Do NOT add choice to this recipe).

**STIR** in various initiatives including a P&A lawsuit and a state plan under "Olmstead" that continues the myth that there are 2,400 people "inappropriately institutionalized," and a bill to close five of the state's facilities for people with developmental disabilities.

Add a **DASH** of budget woes and a call by the state DD Council to "take a lesson from neighboring states" and reduce or close our state facilities to save money.

### Sound familiar?

The "Recipe for Disaster" that I just outlined is from my own state, New Jersey. Yet, I know from reading the news from VOR and other sources that the budget crisis has led to the all-too-familiar battle cry: *Close Institutions, Save Money*.

Advocates against choice in many states are seizing this opportunity to accomplish their "close facilities" agendas, and politicians eager to save a buck are all too eager to listen.

Newspaper headlines and editorials will often leave the average citizen with the impression that closing large facilities will not only save money, but is the right thing to do.

## Make Cake: What advocates can do and how VOR can help

In 2003, VOR educated many elected officials about faulty cost assumptions. The peer reviewed study showed that assumptions that community services were always less expensive were faulty and stemmed from "apples to oranges" comparisons.

Recently, the cost study's lead researcher issued a paper that finds that the "2003 study continues to be valid in 2009 and beyond. That is, cost savings at the macro level are relatively minor when institutional settings are closed and, if there are any at all, they are likely due to staffing costs when comparing state and private caregivers." (Kevin Walsh, Update, 2009) (see p. 3, this issue of *The Voice*).

VOR advocates armed with the original study and the Update can take on cost assumptions directly. Quality of care is also relevant; as family members we must speak up about the quality of care our loved ones receive in specialized facilities.

We must be proactive. Family associations must band together to speak as one voice. Consider cost-effective weekly teleconferences.

Writing editorials to newspapers and publications and pursue guest columns (Op/Eds). VOR can help.

Contacting and visiting our legislators is critical. A long-time VOR member, Sally Chappell, shared with us recently something her state senator once said: "Okay, Sally, you've convinced me by your arguments. Now go make me do it." Puzzled, Sally inquired what he meant. "Show me the votes," was his replay. In short, they listen because we vote, but they need to hear from us.

In New Jersey, we've done all of the above. Advocates are also putting written "Visitor Permission Forms" in their family members' files to prevent anyone not listed on the form from visiting their family members without prior consent (incl. P&A, self advocates and others), and carefully reviewing official plan

ning papers (usually called IPPs or IHPs) to be sure that these written documents accurately reflect their family members' abilities, disabilities, service needs, and desires. This can and should be done in any state.

Whether we are facing good times or the perfect storm, families must be proactive with regard to the needs of their loved ones with developmental disabilities.

*If not us, who?*



Robin Sims

## In this issue

President's Message	2
Cost Study Update	3
Sims on Geraldo	4
National advocacy	5
Heckt: Trusts, Pt. 2	6-7
Fernald case may go to US Supreme Court	8
VOR submits policy recommendations to President Obama	9
VOR Annual Meeting flyer	10
Tributes	13

## Cost Comparisons of Community and Institutional Residential Settings: Historical Review of Selected Research

By Kevin K. Walsh, Theodore A. Kastner and Regina Gentlesk Green  
*Mental Retardation*, Volume 41,  
Number 2: 103-122, April 2003

In the 2003 article noted above a review of selected literature was undertaken to determine the validity of institutional vs. community cost comparisons. A number of methodological problems were identified in the literature reviewed that compromised much of the earlier research on the topic. Additionally, a number of considerations were outlined – source of funds, cost shifting, cost variation, staffing, and case mix – that need to be taken into account when such comparisons are undertaken.

The question has arisen whether the conclusion of this 2003 review, that large savings are not possible within the field of developmental disabilities by shifting from institutional to community settings, remains current.

For the reasons explained below, we find that the 2003 article continues to be valid in 2009 and beyond. That is, cost savings at the macro level are relatively minor when institutional settings are closed and, if there are any at all, they are likely due to staffing costs when comparing state and private caregivers.

As such, the study will continue to be useful in policy discussions in states. Several factors point to why the study's conclusions remain valid in 2009:

### Review Article.

As a review article, the 2003 publication does not generate new data; that is, it reviews previous research. Because of this, the article is more resistant to becoming outdated. Those reading the article, however, would do well to keep in mind that the studies reviewed in the article employ cost figures that existed

at the time the original research articles were published. Therefore, while the findings and conclusions drawn in Walsh, et al. (2003) will continue to be timely, the actual cost figures may need to be adjusted to current levels.

### Stability of the Components.

Because the service and support landscape remains, in large part, similar in 2009 to 2003 and before, the conclusions of Walsh, et al. are likely to hold.

### VOR

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For the most part comparisons reviewed generally compared congregate ICF/MR settings and community-based residential settings (typically group homes) funded under the Medicaid HCBS waiver. Although many states have been moving toward personal budgets and fee-for-service models, group homes continue to be a primary community residential service setting. In this way also the conclusions of the 2003 article continue to be applicable.

### Stability of the Issues.

As noted, the 2003 article presented descriptions of various considerations that affect cost comparisons across states. Because the structural components of the issue have remained unchanged (e.g., institutional settings, group homes) and the funding models have remained largely intact (i.e., Medicaid ICF/MR and HCBS waivers), the various factors affecting them, for the most part, remain as presented in Walsh, et al.

That is, there remains a great deal of

cost variation from institutional to community settings as described in the article; cost shifting, as described in Walsh, et al., is to some extent likely to be structurally fixed in most states owing to the nature of state governments. That is, when certain costs disappear, when individuals are transferred from ICF/MR settings, it is highly likely that these costs will reappear in other state budgets (such as Medicaid). In nearly all instances, this is almost unavoidable. In short, costs don't just disappear when individuals are moved.

Based on the forgoing, it appears that the conclusions drawn in the 2003 article continue to be valid.

KKW, January 23, 2009

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## What YOU can DO!

### GRASSROOTS ADVOCACY CHECKLIST: "If not us, who?"

By Robin Sims, VOR President

**ORGANIZE** a strong statewide organization or coalition of choice advocates, lead by the facility association presidents and leaders of other like-minded groups. Arrange to meet regularly, by teleconference, if necessary.

**ONE MESSAGE, MANY VOICES:** Use the statewide organization to distribute "Action Alerts" to choice advocates around the state. Alerts should contain short, simple template messages and contact information for elected officials. E-mail lists and "phone trees" are also very effective when a message has to get out quickly.

**CHOICE NOTIFICATION FORMS:** Counter the statistics sent around by anti-choice advocates. Poll your members. Send a postcard survey asking family members/guardians of ICFs/MR residents where their family members are best served, the ICFs/MR or community? Tally and publicize the results.

**REACH THE MEDIA** to educate the general public: Write letters to the editor. Contact opinion page editors to inquire about submitting longer guest editorials (Op/Eds).

**YOUR FAMILY MEMBER:** Make sure your family member's official planning documents (IPP, IHP) *expressly detail* her needs and desires, including the services that she now receives in her present home that must be replicated in an alternate setting before any transition from her home will be considered. Have on a file a list of approved visitors.

**CONTACT VOR** for a template "facility support position," cost comparison resources, and other advocacy tools. 877-399-4VOR; <http://www.vor.net>; Tamie327@hotmail.com.

# VOR advocacy efforts

## VOR president appears on Geraldo

Robin Sims represented VOR on the December 27 national broadcast of *Geraldo At Large's* special on "The Waiting List." Joining Robin in the audience was her son, Benny and her husband, Jack; Martha Dwyer, VOR Board Member; and Cindy Bartman, VOR State Coordinator and her husband.

Sims advocated for a range of residential and support options. She complimented Geraldo for his 1969 Willowbrook expose, crediting him for the beautiful campuses and specialized services individuals now benefit from in licensed ICFs/MR "communities."

A video clip, which opened the segment featuring Sims, showed her daughter Heather before she received services at Hunterdon Developmental Center and after. Sims' narration during this segment noted that her children represent the continuum of needs that require a continuum of services. Sims' son, Benny, has Fragile X and resides at home.

Following her appearance on Geraldo, Sims noted her disappointment that the Geraldo segment, which was billed as a "waiting list" special, was really about bashing the facility option.

"Legislators have been sold a bill of goods when it comes to claims that closing centers will free up lots of money," says Sims. "Typically, cost figures given for community services are incomplete. Huge line items, like health care, day activity and supported employment that has no end date and transportation, are not included."

"My daughter and her peers across the country need the specialized services they receive for their survival. They now receive it under one roof. Imagine what it would cost to replicate these same, life sustaining services, in accessible scattered locations across a city."

*Legislators have been sold a bill of goods when it comes to claims that closing centers will free up lots of money.*

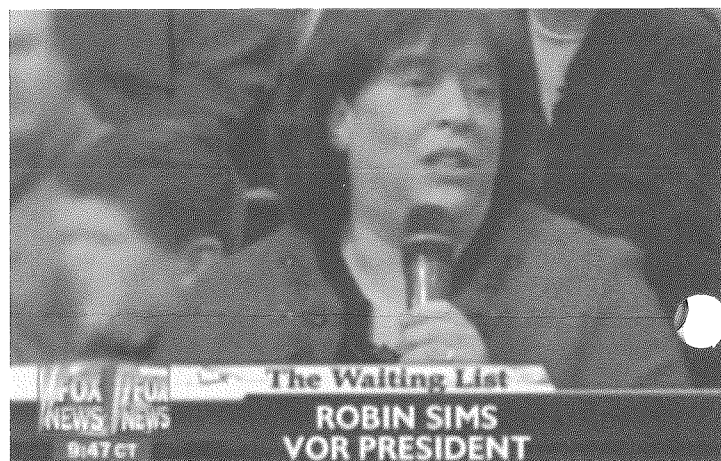
Robin Sims, VOR president

In addition to serving as VOR's president, for Sims, the issue is personal.

"My son, Benny, resides at home with us, but is on a waiting list for community services," she explains. "My daughter, however, needs the specialized care provided at Hunterdon Developmental Center, an institution."

"If advocates who support closing my daughter's home have their way, Heather will lose her services at the Center and be forced into someone else's notion of 'community' where she will suffer. Meanwhile, Benny will wait longer because people who become displaced due to a closure get services, however inadequate, first."

"Heather will suffer and Benny will wait longer. Does that make any sense?" asks Sims.



# Making a difference nationwide

## VOR advocate featured at dental convention

Mary Kay Cowen, representing VOR, was a featured speaker at the November 2008 Annual Seminar of the Southern Association of Institutional Dentists (SAID) in Myrtle Beach, SC.



Mary Kay Cowen

She co-presented with Robert Leonetti, DMD. Their presentation, *S.A.I.D. & Advocacy, Perfect Together*, emphasized the importance of grassroots advocacy and provided "how to" tips.

"The conference was a terrific networking opportunity for VOR, and Mary Kay represented this organization wonderfully," remarked Julie Huso, VOR's director of resource development, who also attended the conference.

## Julie Huso attends S.O. Winter Games

### Donor's Forum

By Julie M. Huso  
Director of  
Resource  
Development

More than 2,000 athletes with intellectual disabilities, representing nearly 100 countries filled the Idaho Center in Boise, ID during the dramatic Parade of Athletes, part of the opening ceremonies of the 2009 Special Olympics World Winter Games.

A delegate from each country was presented a globe that was placed as a symbol and decoration on the Olympic Cauldron. The Flame of Hope traveled more than 37,000 miles, over five continents and 35 countries.

The 2009 Special Olympics World Winter Games is the largest international sporting and humanitarian event this year. Athletes participating in seven sports are supported by coaches, volunteers, and family members. Law enforcement officers from around the globe raised \$34 million to support the event; 55,000 blue and white scarves were also made by people around the world to support the games.



VOR's Julie Huso is ready to join the fun

Julie Huso, director of resource development for VOR, was among the nearly 10,000 people in attendance.

"One of the more memorable moments was watching all of these wonderful athletes represent their countries and with such bright smiles on their faces," Huso stated.

Alpine skiing, figure skating, snowshoeing and snowboarding were some of the events Huso was able to view.

"The talent and ability that each of the athletes brought to the competition was amazing," she said.

Proudly wearing a shirt emblazoned with the VOR logo, Huso fielded many questions about VOR from people attending the Games.

"I had wonderful exchanges with

**Special Olympics** continued on pg 9

## SPONSORSHIP OPPORTUNITIES!

**Organizations, businesses, individuals invited to help sponsor VOR's Annual Conference and Washington Initiative**

Each year, VOR's Annual Conference and Washington Initiative in Washington, D.C., is made possible by the generous financial support of numerous sponsors.

There are many sponsorship categories to choose from, including but not limited to Session, Luncheon, Literature and Participant sponsorship opportunities which range from \$150 - \$1500. In addition, "Medal" sponsorship opportunities are available for gifts exceeding \$1,500. Depending on giving level, Sponsors receive free guest passes to VOR's Annual Conference, the opportunity to distribute literature to conference attendees, and acknowledgment in VOR's national publications and website.

VOR Annual Conference and Washington Initiative sponsors benefit a great cause while reaching family advocates and other leaders from across the country, many of whom share sponsors' literature with their extended advocacy networks back in their home states.

For more details on how to be a 2009 Sponsor, visit, <http://www.vor.net/Sponsors2009.htm>, or contact Julie Huso at 605-370-4652; [husojs@sio.midco.net](mailto:husojs@sio.midco.net). Thank You!

# Pt. 2

# Ignorance of the law for parents of persons with

*This is the second article in a two part series. In the first installment, author Paul Heckt, attorney at law, defined "supplemental needs" and "special needs" trusts as legal vehicles by which disabled loved ones can be provided for financially without risking eligibility for government benefits. This installment discusses the federal enabling legislation which allows for these special trusts. The full article can be found on VOR's website at <http://vor.net/heckt08.htm>.*

The enabling federal legislation permitting "special needs trusts" is United States Code, title 42, section 1396p(c)(2)(B)(iv) or 1396p(d), as amended by section 13611(b) of the Omnibus Budget Reconciliation Act of 1993, Public Law 103-66, commonly known as "OBRA 1993". This was codified in Minnesota by Minn. Stat. §501B.89, Subd. 3. Most states have similar laws.

In both cases, the trusts are permitted because their fundamental purpose is to "supplement, not supplant" benefits provided by governmental agencies. The theory is that the state cannot force parents to leave money to their child with a disability, and if they leave the money to the other siblings, the state can't get their hands on it anyway. Similarly, there would be no incentive for an injured person to sue to recover damages if all of the money that he or she recovered had to be paid to the state. So instead of putting all of that money at risk, the states permit the parents or guardians to put the money into a supplemental needs trust or a special needs trust, as the case may be.

The primary purpose of both trusts is to provide for the reasonable living expenses and other basic needs of a person with a disability when benefits from publicly funded benefit programs are not sufficient to provide adequately for those needs. For example, the

government will not pay for my developmentally disabled daughter to go to a Minnesota Twins baseball game or a Minnesota Gopher hockey game, both of which she loves to attend. They won't pay for her to go on a vacation or an amusement park or to go out to dinner or a movie. They won't pay for my developmentally disabled sister to go to Baker's Square for a piece of French silk pie and a coke, or buy her rock 'n roll CDs at Best Buy. In other words, if it is fun, the government won't pay for it.

I am not suggesting that the government should pay for these types of expenses. The federal government and most state governments are broke enough as it is. Fortunately, through the efforts of state and national organizations like VOR and the ARCs, the government has passed statutes and rules that let us as parents and family members set aside money to provide for those quality of life enhancements without such money causing the loss of governmental benefits for our loved ones with special needs.

One problem I encounter quite frequently is that the lawyers who most people go to for their estate planning needs are not always experienced in drafting supplemental or special needs trusts. This causes problems because the statutes and rules governing these trusts are very specific. For example, both a supplemental needs trust and a special needs trust must contain provisions which prohibit disbursements that would have the effect of replacing, reducing, or substituting for publicly funded benefits otherwise available to the beneficiary or rendering the beneficiary ineligible for publicly funded benefits. (The government generally provides for housing, medical and food.) So the trustee should not use trust funds for these purposes, although there are some creative ways to "enhance" government provided benefits

***If it is fun,  
the government  
won't pay for it.***

without replacing them. The point is that these restrictions are not included in the trust document, then the trust will not qualify for an exemption and those funds will not be covered by Medical Assistance as "assets," which must be spent down. A person with special needs can qualify for benefits.

One way to avoid this problem is to ask the lawyer, before you hire him or her, how many supplemental needs trusts they drafted in the past year, and what percent of the time is spent on disability law. The best approach is to check with friends who have children with special needs to see what lawyer they used, and if they liked them, you can call your local association to see if they ever disability your loved one has. They can give you the names of lawyers who practice in that area. The associations usually do not "endorse" anyone in particular, but they usually share the names of lawyers they know practice in that area. The number of lawyers who practice in this area is small, unfortunately. (In Minnesota there are 25,000 lawyers, 9,000 of whom practice in Hennepin County, where I practice. There are less than 10 lawyers that I would be comfortable enough referring parents of persons with special needs to for estate planning if I could not handle their case. It is a particularly profitable area of law, so if a lawyer has a sibling or child with special needs (I have both), they often do not have the interest or experience in this area.

Another area of difference between supplemental needs trusts and special needs trusts is when they must be created. A special needs trust has to be created for a person with special needs receive benefits from the insurance settlement or estate. With a supplemental needs trust can be established at the time a spouse dies by including the trust in the parents' wills. These are called "testamentary"

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trusts. The advantage is that they cost less and don't have to be funded until after the parents both pass away. The disadvantage is that they cannot be funded until both parents pass away. What happens if the parents run out of money because of nursing home costs? A trust with no money in it is of no benefit. Moreover, if the trust is not set up during the

*...the lawyers who most people go to for their estate planning needs are not always experienced in drafting supplemental or special needs trusts.*

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nothing to receive inheritances from grandparents or siblings or other friends who wish to leave a special bequest to the person with special needs.

The other option is to set up an "inter vivos" or "living" trust for the child with special needs. It costs more, but it has several advantages. First, the trust will be operating and the trustee, usually an adult sibling or close family member, can see how it is supposed to be run. For example, the trustee will learn from the parents and their attorney what kinds of expenditures are permitted and what kinds are not, what types of tax returns are required, if any, and what kinds of records need to be kept. Second, the parents can see how well their chosen trustee is performing and make a change if they are not working out. Third, the trust will most likely be "grandfathered in" if the state changes the law in the future and no longer permits supplemental needs trusts. And fourth, grandparents and other relatives can direct gifts from their own wills to the trustee of the inter vivos trust, which they cannot do if the parents are using a testamentary trust.

From a tax and leverage point of view, the best way to fund an inter vivos supplemental needs trust is with a life insurance policy on the parent. If there are two parents, a second to die policy can be used to save cost and fund the trust at the second death.

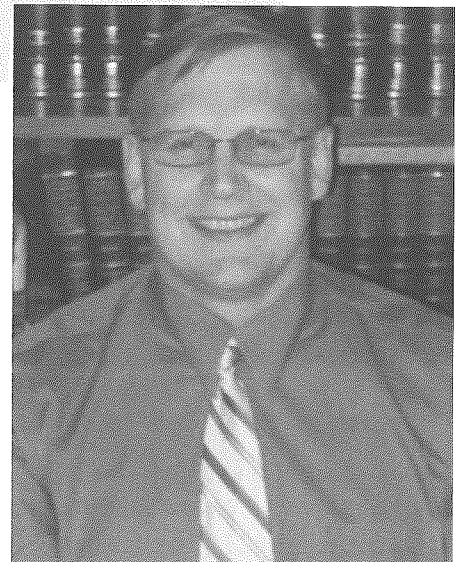
The insurance policy builds up tax free and the proceeds are also tax free. Plus, the money is available in year one, if the parent dies, which would not be the case if the parent tries to fund the trust a little bit at a time, over say, twenty years.

If the parents are not insurable, the second best choice would be an annuity, again because it builds up tax deferred. There would be a tax when the annuitant passed away, which is why we prefer life insurance, but not everyone can obtain life insurance. The younger the person is when they buy it, the less expensive it is to fund.

## About the Author

Paul Heckt is a long time VOR member who is an estate planning attorney in Minneapolis, MN who helps parents of persons with disabilities properly plan their estates. Paul has been practicing law since 1978, starting his career as a prosecutor for the state attorney general. He has a daughter, Ann, with mild developmental disabilities and a sister, Janice, with severe developmental disabilities. His father is Mel Heckt, former VOR board member, who continues to practice law at age 84. Mel wrote the first supplemental needs trust in the state of Minnesota, and he served on the President's Committee on Mental Retardation under Presidents Nixon and Ford.

In summary, all parents and relatives of persons with special needs should make sure that their estate plans don't inadvertently disqualify their special loved ones from receiving governmental benefits. If they don't, their "ignorance of the law" will have very disastrous consequences.



**Rep. Barney Frank (D-MA)  
reintroduces  
his family rights bill**

On Tuesday, March 3, 2009, Rep. Barney Frank reintroduced his "Family Rights" bill.

January marked a new Congress, making it necessary for Rep. Frank to reintroduce his "family rights" bill. The new bill, H.R. 1255 is identical to its predecessor, H.R. 3995.

H.R. 1255 supports the common sense principle that residents of ICFs/MR and their legal guardians (usually close family members) should be the ones to decide whether a class action lawsuit proceeds on their behalf, not federally-funded lawyers.

Titled "Protecting the interests of each resident of ICFs/MR in class action lawsuits on behalf of such resident," the key provisions of the bill are: the entity filing the federally-financed lawsuit must give the affected facility at least 90 days notice before filing the lawsuit; the facility, upon receiving notice, must provide notice to all residents and, where one is appointed, to legal guardians; and the residents (or, where one is appointed, their legal guardians) have 60 days after receiving notice from the facility to elect to not be a part of the lawsuit (opt out).

**ACTION NEEDED:  
CONTACT YOUR  
U.S. REPRESENTATIVE**  
and ask him/her  
to COSPONSOR H.R. 1255

**For Congressional Contact  
Information:**  
<http://www.congress.org>  
202-224-3121  
(U.S. Capitol Switchboard)

**For Questions:**  
Tamie Hopp: 877-399-4VOR (toll free) or Tamie327@hotmail.com

# Legal NEWS

## Massachusetts: Families appeal to U.S. Supreme Court

The fate of the Walter E. Fernald Developmental Center could be in the hands of the U.S. Supreme Court, if it accepts the case brought to it by the Fernald League, a group of families and guardians who have fought for years to keep the center open.

The petition revolves around the question of whether the First U.S. Circuit Court of Appeals overstepped its bounds by not showing "deference" to an August 2007 ruling made by U.S. District Judge Joseph Tauro.

Tauro, who has presided over court proceedings involving Fernald since 1974, ruled in 2007 that the state must give Fernald residents the opportunity to stay there if they so choose. To do that,

Tauro re-opened a 1993 consent decree which guaranteed that residents would receive individualized treatment that must be equal or better elsewhere.

In October 2008, the First U.S. Circuit Court of Appeals overruled

Tauro's decision, saying he lacked the authority to reopen the consent decree. Many argue the appeals court decision essentially paved the way for the state to go ahead with its plans to close Fernald. Indeed, the state announced plans in December to shut down Fernald by July 2010.

The Fernald League argues that the

federal appeals court should have deferred to Tauro's interpretation of his own orders, especially since Tauro has been involved with the case for 35 years.

Leon Friedman, attorney for petitioners, said the Supreme Court is being asked to look at the larger issue of whether federal appeals courts must show some deference to the decisions of



Joanna, pictured, is a Ricci class member.

Photo courtesy of George Mavridis.



Marilyn Meagher, president of the Fernald League, attends a press conference in Boston to announce that the league will file an appeal with the U.S. Supreme Court to keep Fernald open. Meagher's sister is Gail Arone, 59, a Fernald resident for over 50 years.

Photo courtesy: Ken McGagh/Daily News staff

district court judges in public-interest, consent decree cases. The 12 circuit courts of appeal are split on this issue.

If the U.S. Supreme Court takes the appeal, Friedman said that could stymie the state's plans to close Fernald and transfer its approximately 160 residents to other facilities. (Source: *Daily News Tribune*, Feb. 3, 2009).

## VOR files Amicus in Fernald case

In late February, VOR filed an *Amicus Curiae* ("friend of the court") brief, in support of the Fernald League's Petition. Consistent with the Petitioners, VOR pointed to the significant divide among federal appellate courts with regard to an appropriate standard of review. VOR argued that the District Court should have been afforded far more deference given the District Court Judge's active management of the case for more than 35 years. VOR also argued that "the policy concerns influencing the decision below rest upon an erroneous reading of this Court's decision in *Olmstead*."



## Florida: Lawsuit challenging budget cuts dismissed

A circuit court judge dismissed Florida P&A's lawsuit against the state over cuts to services for the developmentally disabled. P&A had argued that state cuts would cause "immediate irreparable harm" to about 3,600 disabled Floridians.

P&A claimed that the state had unfairly denied thousands of people a

## VOR

### Contact Information

#### Membership Dues/Contributions

836 S. Arlington Heights Rd., #351  
Elk Grove Village, IL 60007  
847-253-0675 fax

#### Development

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

#### Washington, DC

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

#### Govt. Relations/Advocacy

Tamie Hopp  
P.O. Box 1208  
Rapid City, SD 57709  
605-399-1624 voice  
605-399-1631 fax  
Tamie327@hotmail.com

#### VOR

836 S. Arlington Heights #351  
Elk Grove Village, IL 60007  
847-253-0675 fax  
877-399-4VOR toll free

President:  
Robin Sims  
Editor:  
Rochelle Hagel

Can be read at our website.

Go to:

<http://www.vor.net/StateNewsSpring09.htm>

hearing to appeal new limits on the services they can re-

ceive. The court dismissed the case finding that plaintiffs had not exhausted their options for hearing their grievances through state channels.

Meanwhile, P&A is pursuing a similar case on slightly different grounds on behalf of an individual with developmental disabilities whose services were being cut by \$6,000. The Petition requests the Court to direct the State to grant the individual's request for a hearing. (Source: *Tampa Tribune*, Jan. 24, 2009).

## VOR submits policy recommendations to President Obama

On January 9, 2009, VOR submitted the written policy recommendations to then President-elect Obama. VOR's recommendations were provided as a follow-up to a meeting between VOR leaders and Kareem Dale, who has since been appointed Special Assistant to the President for Disability Policy. VOR called on the new President to support the continuation of ICFs/MR and oppose legislative proposals, such as the Community Choice Act, which work to undermine residential choice. VOR's detailed recommendations can be found at <http://www.vor.net/VORRECOMMENDATIONS.htm>.

## State budget crisis impacting Medicaid; Stimulus provides some help

A new *Families USA* report, *A Painful Recession: States Cut Health Care Safety Net Programs*, analyzes the impact of the current recession on states by examining cuts to their Medicaid programs. The report indicates that more than one million people are at risk of completely losing health coverage, while many more will see reduced benefits.

One way that states are cutting their

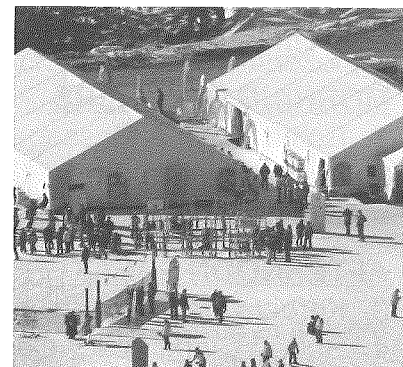
Medicaid programs is through reduced enrollment and

more stringent eligibility. Since the report was published, Congress did approve as part of the larger Stimulus law, an \$87 billion increase in federal dollars for state Medicaid programs until the end of 2010. To receive this additional money, States are not able to change eligibility requirements.

**Special Olympics** continued from pg 5

many people who were interested in VOR's history and shared our perspective with regard to individual and family choice of services, regardless of setting."

"This entire experience was a real



Birds-eye view of the grounds at 2009's S.O. World Winter Games

joy," said Huso. "It seemed everyone attending the Games, from the spectators to the athletes, were really united as advocates, cheering for everyone to have fun and do their best."

"It was a break from reality that I'll treasure for a long time. Not once did I think about the war, the economy, or the battles so many VOR advocates are facing in their states. I left with a renewed sense of hope."



Speaking Out for People  
with Mental Retardation

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877-399-4VOR

Website  
<http://www.vor.net>

Govt Relations/Advocacy  
Washington, D.C.  
P.O. Box 1208  
Rapid City, SD 57709  
605-399-1624 phone  
605-399-1631 fax  
Tamie327@hotmail.com

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

Tax Deductible Dues/Contributions  
836 S. Arlington Heights Rd., #351  
Elk Grove Village, IL  
847-253-0675 fax  
husoj@sio.midco.net

## VOR 2009 Annual Meeting and Washington Initiative June 12 -17, 2009

### JOIN VOICES AND MAKE A DIFFERENCE! PLEASE JOIN US!

All VOR meetings will take place at the Liaison on Capitol Hill, 415 New Jersey Ave., NW, Washington, D.C.  
(Formerly the Holiday Inn on the Hill)

#### Friday, June 12, 2009

##### VOR Annual Board Meeting

1 – 3 pm

VOR members welcome to observe.

##### Taking the Fear out of Fundraising, by Julie Huso

3 – 4 pm

Development training for VOR board members. VOR members also welcome to participate.

##### Reports from the States

6 – 8 pm

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 2009 ANNUAL MEETING

Knowing the Players: Effective Advocacy in Changing Times

#### Saturday June 13, 2009

9 am – 4 pm

##### Annual Meeting

Speakers/Presentations:

##### MORNING SPEAKERS

1. Robin Sims: A Message from VOR's President
2. Susan Daniels, Ph.D., Daniels & Associates: The DD Act's Effectiveness: An update on her research and an opportunity for advocate input.

##### AFTERNOON SPEAKERS

3. Kareem Dale, Special Assistant to the President for Disability Policy (invited)
4. Robert Clark, Policy Coordinator for the Health Subcommittee of the House Energy and Commerce Committee (Rep. Frank Pallone (D-NJ), Chair) (invited)

#### Saturday June 13, 2009

6:00

##### VOR Networking Dinner – location TB

VOR will host a dinner to allow VOR members to continue networking with like-minded advocates from across the country. Participation is optional; there will be an additional cost of about \$25. Details will be provided in advance to participants.

#### Sunday, June 14, 2009

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. Legislative priorities will include the Rep. Barney Frank's class action reform legislation and the DD Act Reauthorization.

#### Begins Monday, June 15, 2009

##### 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.

**Monday, June 15, 2009**  
**3rd Annual Capitol Hill Reception**  
**B369 Rayburn House Office Building**

5 – 7 pm

Relax and network with VOR members, Congressional Members and their staff, after your busy day on Capitol Hill. A light dinner will be provided.

**Monday, June 15, 2009**  
**Tuesday, June 16, 2009**

7:30 pm  
6:30 – 8 pm

Informal De-briefing

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

### HOTEL INFORMATION

The Liaison on Capitol Hill (formerly Holiday Inn on the Hill) 866-AFFINIA (233-4642) (toll-free)  
415 New Jersey Ave., N.W. Washington, D.C. 20001  
Reservations due by May 12, 2009

Group rate: \$179 for single or double, plus tax, per night. Mention VOR for group rate. All meetings will be held at the The Liaison on Capitol Hill. 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

Taxis and "Super Shuttle" vans are available at Reagan International Airport. "Super Shuttle" is \$14 per person. 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 VOR \* 836 S. Arlington Heights Rd., #351 \* Elk Grove Village, IL 60007

Fax: 605-399-1631 \* Tamie327@hotmail.com \* Phone: 877-399-4867 (toll free) or 605-399-1624; a 501(c)(3) org.

Name(s) \_\_\_\_\_

Address \_\_\_\_\_

City, State, Zip \_\_\_\_\_

Home Phone \_\_\_\_\_

Work Phone \_\_\_\_\_

Email \_\_\_\_\_

Family/professional org/company (if applicable) \_\_\_\_\_

Mark all that apply:

\_\_\_ \$50 per person for member registration at the Annual Meeting on Saturday, June 13 if paid by 5/31.

<2009 WASH-REG>

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

<2009 WASH-REG>

\_\_\_ \$75 per person for non-member registration at the Annual Meeting on Saturday, June 13 includes one-year membership if paid by 5/31.

<2009 WASH-REG>

\_\_\_ \$85 per person for non-member registration after 5/31. Membership included.

<2009 WASH-REG>

\_\_\_ A donation of \$\_\_\_\_\_ is enclosed.

<2009 WASH-DONA>

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

Charge card: MC  Visa

Expiration Date \_\_\_\_\_

Credit card number \_\_\_\_\_

Signature \_\_\_\_\_

**VOR Welcomes Tribute Donations**  
Gifts have been received

**In Memory of**  
Jeffrey Hyatt Arnold

Edith Miller

Billy Smalley

who would have been 70 on Nov. 4, 2008

Louise Underwood  
(<http://www.vor.net/LouiseTribute.htm>)

**In Honor of**

Annette Barnet

Colleen Cross

Marilyn and Bob Cross

Ray Duffey

Mr. and Mrs. Norman Fox

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Jason Kinzler

Tom Simon

Dan Walsworth

Rosalie Wolff

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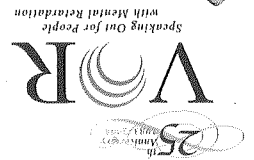
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847-253-0675 Fax

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