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# Playing with the Big Dogs

## PRESIDENT'S MESSAGE

By Robin Sims, President

Beth Weinstein, an old friend who some of you may remember, sent me an article that reminded her of VOR and our approach to advocacy. Titled "Building Relationships with the Big Dogs," it states:

When it's time for lawmakers to make their decisions, they turn to the people they know and trust. Several 'underdog' advocates at associations have found that developing long-term relationships with lawmakers, sometimes years in advance can make the difference in tipping the next big decision in their favor." (*Associations Now*, August 2009).

Unquestionably, VOR is the "underdog."

According to United Cerebral Palsy, "Individuals with intellectual and developmental disabilities make up one percent of all Medicaid recipients." VOR is the only national advocacy organization representing the tiny fraction of people within that one percent who are best served in licensed facility-based care; they are the most vulnerable among all Medicaid recipients.

Thus, we face a triple threat in our advocacy:

- (1) Our position in support of facility-based care is not "PC;" we represent the minority position.
- (2) Our primary constituency represents a very tiny percentage of the people requiring Medicaid supports.
- (3) This tiny percentage requires expensive care for their very survival.

### What we do have going for us: The moral high ground

Even as the underdog, VOR owns the moral high ground.

We define choice honestly and based on individualized needs. We provide compelling evidence that the "community" works for some, but not for all people. VOR advocates are dedicated families of people with profound developmental disabilities whose only stake in this game is the survival and happiness of their loved ones.

The "rightness" of our position has earned us credibility in many federal, state and local offices, and with certain national organizations. Our approach has been strategic, sometimes quietly leveraging relationships we have cultivated over time. As noted by the "Big Dog" article cited above, developing these relationships can often take years.

*"Often when we think of the 'little guy' or the 'underdog' who wins over the powers that be, we think of a dramatic, intrepid, hair-on-fire character. In reality, successful influencers are nothing like that. They are methodical. They are humble. They are patient. They know achieving their goals is a long-term process, so their methodology includes building long-term relationships . . ."* (*Associations Now*, August 2009)

Being patient is not easy in light of the urgency of our issues. Still, being strategic is essential to any organization's success, and sometimes strategy requires patience. Being loud doesn't always equate to getting your way. There are times when grassroots leverage (quantity) is absolutely required. At other times, the quiet approach (quality) is more effective. Very often, a blend of both quantity and quality is what is needed.

### Conclusion: For VOR, patience and relationships have paid off

Our annual trips to Washington, D.C., along with other activities throughout the year, have put VOR in a position of credibility and respect. VOR leaders and members are readily granted opportunities to make our presentations before Members of Congress, Health and Human Services, CMS, the Department of Justice and the White House, and before national organizations such as the National Governors Association and the Consortium for Citizens with Disabilities. Even in those offices where we have fundamental differences of opinion on some issues, we have developed relationships where meaningful alliances can happen on issues of common concern, such as adequate funding for Medicaid and Social Security.

VOR leaders remain in communication throughout the year with Congress-



Robin Sims

sional and federal offices to maintain these established relationships, and cultivate new ones.

Our efforts have and are paying off in terms of our advocacy. We are also using the same strategy to build "financial friends" and we see the results of that with each passing month. Supporting our mission *in advocacy and financially* is what we do each and everyday.

**Thanks to all of you who make that happen.**

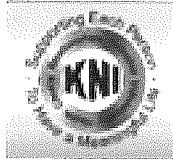
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*On the Cover:* Frank David Selman with his Aunt Alicia.

# Foster Grandparents: Part of everyday life at KNI

The mission of the Kansas Neurological Institute (KNI), a state operated facility, is to help everyone who lives there have a meaningful life. The KNI Foster Grandparent Program (FGP) plays an important role in helping KNI achieve this mission.



– and often much more – with the people who live at KNI. Foster grandparents take their “grandchildren” on daily walks around campus, read to them, attend informal gatherings where they sing songs or listen to music, and are part of their daily lives.

The seniors who volunteer their time at KNI are part of the FGP of Northeast Kansas, an affiliate of the Senior Corps and funded by the Corporation for National and Community Service.

“Our program is unique,” said Connie Stewart, director of KNI. “The FGP at KNI is one of only a very few remaining facility-based programs around the country. KNI has sponsored us for 43 years.”

In addition to KNI, the FGP of Northeast Kansas serves 12 counties in its region. “We have tripled in size since 1966, to meet our growing community needs,” Stewart added. “Our service at KNI, however, is special.”

“The foster grandparents are always around to lend a hand with any kind of celebration,” said Libby Tidwell, editor of the KNI News, the newsletter of the Parent and Guardians group. “They are the most energetic and loving group of folks I’ve ever seen and

*“We are very blessed to have them here on campus.”*

Libby Tidwell, editor, KNI News

“There is a real sense of community with these volunteers,” noted Tidwell. “The foster grandparents will sit with their KNI friends in groups and chatter about the events in the news

while everyone enjoys the morning sun and fellowship that being a part of KNI’s daily life brings.”

“It truly is a wonderful program,” said Bill McGuire, Sr.,



Caroline and FGP Orville

whose son Michael lives at KNI and participates in the foster grandparent program.

Margaret Walters, a FGP volunteer, visits Michael every day.

“She arrives every day at 9:00 am like clockwork,” McGuire says.

“Michael is like a son to her. We see Michael once each week, but Margaret can be there daily. We often call her to find out how he’s doing.”

When asked about Michael, Walters smiles. “He is so special to me,” she says. “If I can get him to smile, it just makes my whole day.”

“The bonds that are formed are strong. Foster grandparents get as much out of the relationship as the individuals we are visiting and spending time with,” says Walters. “It truly is a wonderful program.”

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**Happy Holidays  
to all VOR members & advocates  
from your Board & Staff!**

[www.vor.net/vor-contacts/directories/](http://www.vor.net/vor-contacts/directories/)



FGP Margaret Walters and Michael

**Foster Grandparents**  
Share Today. Shape Tomorrow.

we are very blessed to have them here on campus.”

Foster grandparents take part in the annual KNI

picnic, help with the charity fund-raising activities that go on year-round, bring people to the annual Firefighter’s Christmas party, and take part in a myriad of other campus activities.

Their assistance with these special events is greatly appreciated, however, “it is not what makes these volunteers so very special,” noted Stewart. “It is their day-to-day interaction with their ‘grandchildren’ that really makes a difference.”

The commitment of time and compassion is significant. FGP volunteers regularly spend at least 20 hours every week



Rick and FGP Londell

## Virginia: P&A files lawsuit against center

The Virginia Office of Protection and Advocacy (P&A), representing the Arc of Virginia, filed a lawsuit on October 27 alleging that Virginia's plans to rebuild and renovate Southeastern Virginia Training Center (SEVTC) violates the Americans with Disabilities Act.

Although the governor had proposed closing SEVTC earlier this year, the Virginia legislature reversed that decision and required in the Appropriations Act the construction of a new 75-bed facility at SEVTC, as well as some smaller waiver and ICFs/MR community homes. Currently, there are approximately 150 residents at SEVTC.

Unlike similar cases, P&A does not seek class certification in this case. Instead, it seeks a preliminary injunction (a halting) of the rebuilding of SEVTC and Declaratory Judgment that the actions of the state violate federal law.

VOR is in communication with SEVTC families and other Virginia advocates regarding this lawsuit and have pledged our support.

## California: Court battles surround furloughs

A flurry of court fights, union-filed grievances and even a federal intervention are complicating the Schwarzenegger administration's budget-balancing action requiring state employees to take three Fridays each month off without pay, which amounts to about a 14 percent pay cut and the administration says saves the state about \$2 billion annually.

The Social Security Administration has filed a "statement of interest" in an action filed by the Union of American Physicians claiming that furloughs of personnel in the state Disability Determination Services Division "does not save the state a single penny and actually costs the state money."

Several other lawsuits by unions and professional associations are also pending. (*Capitol Weekly*, October 29, 2009)

## Pennsylvania: Families file for intervention in P&A lawsuit

On June 22, 2009, the Pennsylvania Disability Rights Network (DRN) (P&A) filed a lawsuit against the State's Department of Public Welfare (DPW) alleging that the rights of all individuals who receive residential care provided by the five state ICFs/MR, have been violated because they have not been offered the opportunity to move to appropriate community living arrangements.

In response, with VOR's help, 10 family members and guardians of residents from each of the five centers have

*Plaintiffs are attempting to . . . reduce those options in furtherance of their ideology that all ICF/MR residents should and 'could live in more integrated settings.'*

joined in a Motion to Intervene. The "Springstead Intervenors" named for the lead intervernor, Craig Springstead, wish to remain where they live, and seek to intervene to protect that right.

According to their brief in support of their motion, the Springstead Intervenors "are not advocating exclusively for institutional care, or exclusively community care, but rather (and only) the best care – as chosen by the individuals, their guardians, and their medical professionals." "Plaintiffs are attempting to . . . reduce those options in furtherance of their ideology that all ICF/MR residents should and 'could live in more integrated settings.'" Likewise, the state "appears to acquiesce in Plaintiffs' assertion that community placement is appropriate for all persons residing in the state-operated ICFs/MR," claiming it would "discharge [ICFs/MR residents] to community placements" given sufficient funding to create community placements.

A ruling on the motion to intervene is pending.

## Pennsylvania: No law to protect vulnerable adults

Pennsylvania is one of only five states in the nation without an adult-protection law that gives county or regional agencies the authority to investigate and record incidents of alleged abuse or neglect of adults with intellectual and developmental disabilities. Suspected abusers without a criminal record can pass a background check to work in another group home or private residence.

If a statewide Adult Protective Services system were created, cases of alleged abuse or neglect would be recorded and future employers would have access to that information, even if criminal charges weren't filed.

Adult-protective-services bills have been introduced in the state House and Senate, but both are stuck in committee due to concerns over costs. The need is unquestioned. In 2003, a legislative report estimated that a new system would receive about 4,000 abuse reports a year involving people between the ages of 18 and 59, and that about 1,200 of them would be substantiated. (*Philadelphia Daily News*, September 24, 2009).

## Question for Members

*In your state, if an individual with developmental disabilities has no family and needs guardianship, who steps in?*

*A "state guardian," "corporate guardian," other? We'd like to hear from you. Please send your response to Tamie327@hotmail.com.*

California:

Legal News continued on page 5

## VOR Rep. visits KNI

Mary Kay Cowen, Chairperson of VOR's Membership Committee, spoke to KNI families on Nov. 14.

Cowen's presentation included a grassroots advocacy training, focusing on what families could do collectively to challenge the recent recommendation to close KNI.

Efforts, she suggested, must necessarily and immediately focus on the Governor and Legislator. She also asked families to consider other groups to coalesce with, noting there is strength in numbers.

## Idaho: Moves to close home for the disabled, relatives anxious

Monty Sweitzer is 45 and severely intellectually disabled. He has been a resident of Idaho State School and Hospital since age 11.

He cannot tie his shoelaces, and he communicates with one-word sentences, grunts and a pocket-sized picture book. Now Idaho is making a new push to close his home of 29 years, its only institution for the developmentally disabled, as part of budget-cutting efforts. His family is praying it will not happen.

At ISSH, Dona Butler, Monte's sister and guardian, knows her brother gets to go horseback riding once a month in the summer, and in the winter goes cross-country skiing four times each month. She also knows the employees get benefits and are paid more than the standard \$10 or \$12 hourly wages paid in many private group homes.

"I've looked [into private providers] and when I ask, 'Can you guarantee me that your business will be here in five or 10 or 15 years, that you won't bottom out or burn out and give up?' they never can promise," Butler said. "When I ask if he'll be taken horseback riding or bowling, they say they don't know, it depends. I'm sorry, but that's not good enough." (Source: *Associated Press*, August 4, 2009).

## Kansas:

### Panel recommends closing KNI; Legislature must approve

A state commission has recommended closing the Kansas Neurological Institute in Topeka, which serves nearly 160 people with severe developmental disabilities. If approved, the plan could shut down KNI within three years. KNI residents would be transferred either to more community- or home-based settings or to Parsons State Hospital under the recommendation.

*...a "significant amount of the report is grossly inaccurate. We don't want to waste taxpayers' money for information that isn't accurate."*

**Jodi Fenner, director, Neb. DHHS Division of Developmental Disabilities**

The measure, approved 7-3 by the Facilities Closure and Realignment Commission, will now go to Gov. Mark Parkinson. If Parkinson approves the recommendation and issues an executive order, the Legislature would have to pass a bill to stop it from going forward.

The plan also calls for downsizing Parsons State Hospital by moving residents into smaller group homes, although it wouldn't close the hospital.

Parents and guardians of people served at KNI were upset by the commission's vote, but have vowed to challenge it.

## Nebraska:

### Beatrice report draws fire

A report on progress at the Beatrice State Developmental Center by court expert John McGee contains inaccurate statistics and information, said Jodi Fenner, director of the state Department of Health and Human Services' Division of Developmental Disabilities.

"We are dealing with consistent inaccuracies, and I'm a little fed up," she said in a telephone interview shortly after the report was released. Health and Human Services has reported its concerns to the judge handling the BSDC settlement and will provide the court and the public with

its own report to correct inaccuracies.

The state has sent \$294,434.48 to the court for payment to McGee, who uses a team of experts to follow progress at the institution and of people moved into the community. BSDC staff members have received valuable information from experts on McGee's team, particularly on the community transition process, she said. But a "significant amount of the report is grossly inaccurate," she said. "We don't want to waste taxpayers' money for information that isn't accurate." (*Lincoln Journal-Star*, October 23, 2009)

**Legal News** continued from page 45

### Autism denials illegal, says court

A Los Angeles County Superior Court judge issued a ruling finding that the California has illegally sided with health insurance companies that deny coverage for Applied Behavioral Analysis ("ABA"), a type of treatment for autistic children. A memo circulated by the California Department of Managed Health Care (DMHC) to health insurers was also ruled to be an illegal "underground regulation" because it violated state law requiring a public process for changing insurance regulations.

The suit alleged that the DMHC illegally changed the agency's policy to permit insurers to deny coverage for medically necessary ABA treatments on the ground that the health care professionals who administer the treatments are not licensed by the state but by a nationwide certification board.

This is one of several justifications recently cited by the insurers to deny coverage for ABA therapy in plain violation of the California Mental Health Parity Act. (*Consumer Watchdog*, Oct. 27, 2009).

# Frank David's Story

With love from family, friends & support, safety of group home

# "Life is go

My son, Frank David Selman, is autistic and has mental retardation. At twenty-four, Frank David is one of the thousands of developmentally disabled adults living in this nation's Intermediate Care Facilities for the Mentally Retarded (ICFs/MR). Although they make up only a small percentage of America's population, all their stories are important, but I can tell only one. Here is Frank David's.

Born three weeks early, Frank David came into the world with several noticeable handicaps, as well as others not immediately apparent. He showed little interest in food and gained no weight during the first month, prompting his doctors to label him a "failure to thrive" baby. Over the next year he would undergo surgery to correct a heart murmur and be fitted with braces for a clubfoot. He suffered frequent respiratory infections and intestinal problems, and he never slept for more than two hours straight. (He would be 13 before he slept through the night.) A month rarely passed that we didn't make the 270-mile round trip to Arkansas Children's Hospital in Little Rock for treatment of his various problems. He was so tiny, so frail, so different from other babies.

But, oh, how he was loved! His grandparents, his teenage brothers and sister, and my husband Frank and I kept trying to find new ways to engage his attention and to make him laugh. To his toys and other toddlers he was largely indifferent. He often shrieked in fear over an unfamiliar object or situation and could be calmed only by a car ride, lulled by its motion and comforted by its enclosed space. In fact, we learned early in his life that he was his happiest, most predictable self when strapped in his car seat, cruising down the road, and listening to country music. His odd speech (reversal of pronouns, echolalia, and difficulty in connecting words into even short sentences) and his compulsive behavior worried us; his illnesses left us drained and

frightened. However, his good moments made all our efforts worthwhile. When he laughed, life was good.

The years passed. We all became adept at devising new strategies to manage him at every stage of childhood. With the loving help of many caregivers, childcare programs, family, and a supportive community, Frank was able to build a thriving optometric practice, and I continued as an English professor at Southern Arkansas University in our hometown of Magnolia.

At age six, Frank David's size and health had improved enough for him to enter kindergarten, where, after a few rough weeks of disruptive behavior, he was assigned the first of the succession

*By the time he was in elementary school he could name every brand and model of vehicles, identify their keys, and tell us who drove what.*

of teaching aides who would be with him throughout his public school career. When he was eight, after many doctors, tests, and evaluations, we finally received the official diagnosis we long expected: moderate to severe autism and mental retardation, qualifying him for a full array of special education programs and therapists provided through the schools. Although more than a few times he became so uncontrollable that we would be called to take him home, his teachers' patience and the predictable structure of school life kept him happy. He believed the entire Magnolia school system had been set up just for him.

Numbers meant little to him, and he never learned to process whole sentences. But he could easily read single words, familiar phrases, logos, and common signs. Everyone celebrated the day in the fifth grade when he wrote his name all by himself.

What continued to enthrall him were cars. By the time he was in elementary school he could name every brand and model of vehicles, identify their keys, and tell us who drove what. Getting rides in our friends' cars became his greatest treat. He found rental cars espe-

*When U-Save Car and Truck Rental opened an office in Magnolia in 2001, Frank David was overjoyed.*

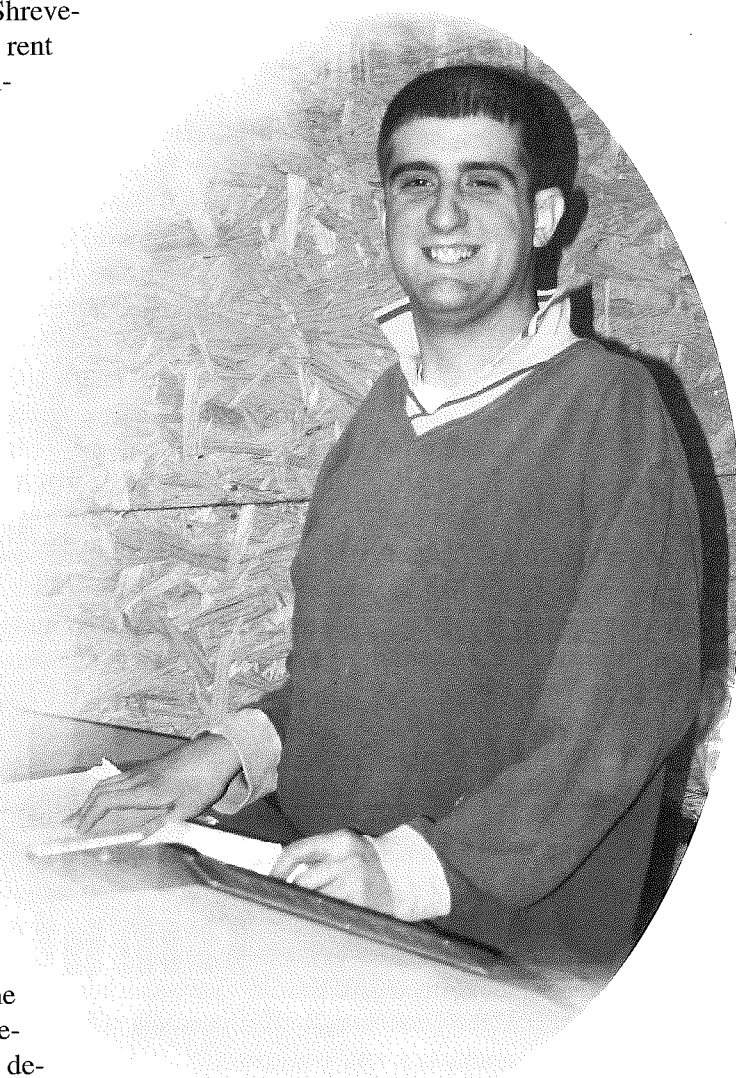
cially absorbing. Of the 90 cars for the long drive to handle. They kept him content for the entire vacation. U-Save Car and Truck Rental has an office in Magnolia in 2001. Frank David was overjoyed. He was driving U-Save's cars and keys quickly developed into a ritual. For the grand opening of a larger office near the city, the agency's founder sent him a company jacket and wrote a story about him for its newsletter. It appeared in the fall issue of 2005 with the headline, "Our Greatest Find of All."

His graduation in May was crowned an exciting season of homecoming, school pictures, the obligatory other 2005 parade, a parade recognition day, and a parade complete with a date, flowers, tuxedo. Proudly dressed in a gown, he played his part in the final ceremony. It was the high point of his life at that time. Because of his special needs, we decided to keep him in his room.

But we misjudged the absence of his former room. Throughout his life he had uncontrollable behavior. These autistic explosions were not them. In the autumn of 2005, the number of cars increased in number and put him in increasing danger on the highway in front of our house. Several times he tried to jump into neighboring homes. Several times he tried to jump into a parked car that he couldn't manage himself. My husband and I

By Linda Selman

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... could no longer  
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 ... suitable place for his long term care.

Thus began months of painstaking research, visits and interviews, medical evaluations, and endless forms. We finally decided to apply to the Arkadelphia Human Development Center (AHDC), closest of Arkansas’s six large intermediate care facilities. These institutions provide 24-hour supervision, job training classes for residents who are physically able, medical monitoring, on-campus staff of nurses, quick access to doctors and dentists, and a wide range of lively social activities. One tearful September

Story continues on page 9

# Ruth Meet Attias:

## Committed to daughter’s choice of care

Long time VOR member, Ruth Attias, is 86 years old and going strong.

She knows her daughter, Barbara, needs her and that keeps her going. Barbara, a resident of Fairview Developmental Center in Costa Mesa, California, has Down syndrome with profound mental retardation, along with a number of medical and behavioral challenges. At 49 years old, Barbara is non-verbal with cognitive abilities of a child less than 2 years old.

*Ruth has experienced firsthand the injustice of having a government agency (in this case, a Regional Center) challenge what she knows to be in the best interest of her daughter.*

“She’s a handful, but very loveable,” says Ruth.

In addition to her other challenges, Barbara scavenges for food and beverages, sometimes taking from other residents at the Fairview Developmental Center in Costa Mesa, California. “She’ll even take leftovers from the trash,” says her mother. “That’s a problem because she can’t masticate. Her food has to be ground up or she’ll choke.”

She is also an escape risk.

**“One time she was hit by a car. But now Regional Center wants to put her in a house that will not lock from the inside because it is against the law. The front gate also can’t be locked. Does that sound safe?”**

—Ruth Attias

“One time she was hit by a car,” recalls Ruth. “But now Regional Center wants to put her in a house that will not lock from the inside because it is against the law. The front gate also can’t be locked. Does that sound safe?”

Ruth is referring to her present legal battle with the Westside Regional Center which is trying to force Barbara out of Fairview Developmental Center and into a community-living arrangement.

Continued on page 11

## H.R. 1255 picking up speed

H.R. 1255 continues to gain momentum in the House, where it now has 71 cosponsors, including 11 Judiciary Committee members, where H.R. 1255 will first be reviewed. Some senators have also expressed an interest in taking a closer look at the bill.

"VOR's Legislative Committee has done a tremendous job coordinating VOR's overall advocacy in support of H.R. 1255," said Tamie Hopp, VOR's director of government relations and advocacy. "Key to this strategy has been individual members reaching out to their Congressmen on this issue. Our grassroots has really come through. 71 cosponsors is pretty amazing."

For information about H.R. 1255 and a current list of cosponsors, please visit <http://www.vor.net/legislative-voice/legislation/>.

## Appropriations

Despite DD Council requests for an additional \$6 million, the Senate bill only includes an increase of \$1.5 million for councils and the House version recommends no increase. Leading up to and during the June Initiative, VOR urged Congress to "exercise caution" noting that none of the DD Act programs, including state councils, have been subject to Congressional oversight in nearly a decade. Reauthorization (congressional review) of these programs was due in 2007, but is not expected until sometime in 2010.

**For information  
about H.R. 1255  
and a current list  
of cosponsors,  
please visit:**

**[www.vor.net/legislative-voice/legislation/](http://www.vor.net/legislative-voice/legislation/)**

## Health care reform and long term care

There are only a few provisions which potentially impact Medicaid long term care within the several health care reform proposals making their way through Congress. One Senate bill contains the Community First Option (CFO) which proposes a Medicaid community-based attendant services benefit, provided at the option of a state. The new benefit is subject to an enhanced federal Medicaid match.

CFO is included as a "Sense of Congress" provision in the House health care bill that recently passed. A "Sense of Congress" provision expresses the House's hope that CFO will be included in the final health care bill; it is not enforceable.

If CFO remains in the Senate bill, then House and Senate negotiators will

have to consider whether it should be part of the final law.

The other notable provision in the Senate bill is also a "Sense" provision.

The "Sense of the Senate" cites an "institutional bias" specific to nursing home versus community spending for "elderly individuals and adults with physical disabilities." This language is significant because for many years VOR has worked to educate Congress about the "myth of an institutional bias" for people with developmental disabilities, arguing that most comparisons inappropriately compare programs for the elderly, physically disabled and developmentally disabled, which skews the results relative to people with MR/DD and the programs they require, including ICFs/MR.

## GREAT FREE GIFT IDEA

**Don't like computers  
but want VOR news fast?  
Here's a GREAT (and free)  
holiday gift idea!**

As a gift to you this holiday season, ask someone in your family, or a close friend, to receive and print for you VOR's Weekly E-Mail Update every Friday. They can also help you regularly visit VOR's website, which is a great, frequently updated, advocacy resource ([www.vor.net](http://www.vor.net)).

This gift idea keeps you informed on up-to-the-minute advocacy news and tools, while also giving you quality time with your grandchild, child, niece or other close family member or friend.

To get started right away, have them send an email to [Tamie327@hotmail.com](mailto:Tamie327@hotmail.com), with GREAT GIFT in the subject line and your name in the text of the email. **THANK YOU!**

## Tributes

**In Celebration  
of the Marriage  
of Jacob and Christine  
Biercer**

**In Honor  
of Ed and Virginia  
Carraway**

**In Memory  
of Jordan and Frank  
Engels**



## Frank David's Story continued from page 7

morning when I had struggled to prevent him from entering a neighbor's house down the road, a providential call came from Arkadelphia. A young men's group home on its 330-acre campus had a place for him. We moved him into it that day and wept all 80 miles of the journey home, wondering how we could have done such a thing. Our answer came the next weekend, when we returned to Arkadelphia for the family day picnic and found Frank David too busy with his new friends to spend much time with us. We were thrilled.

Frank David has lived there for almost three years now and has settled in the comfortable routine of his life very well. He still has his odd moments, like the time he flushed all his housemates' toothbrushes down the toilet, but in general he behaves himself. As he did in the public schools, he has attached himself to the center's staff, who number over 100 (roughly equal to the number of residents) and whose schedules, cars, and keys he quickly memorized. His favorite activity, of course, is getting to go anywhere in one of the official state cars or vans. He has participated in some great field trips—to Little Rock for the

State Fair, the zoo,

and the Harlem Globetrotters' exhibition; to Hot Springs to enjoy the crowd and eat the fifty-cent corned beef sandwiches that are sold the opening day of the horse races; to local movies; to nearby Lake DeGray for picnics and Independence Day fireworks; to football, basketball, and baseball games at Arkadelphia High School and at Henderson and Ouachita Baptist Universities; and to many Special Olympics events all over the state.

The on-campus rewards for residents whose behavior has been exemplary are also considerable: cafeteria passes for lunch with the staff and vehicle passes for in-town forays to Sonic.

Because AHDC is now in partnership with Clark County's recycling efforts, his work week duties have expanded from the wood working shop to include the recycling center, and he is enjoying the opportunities he has to be outside, tearing apart boxes and bundling cardboard. We see him often, at least twice

every month, and still include him in most family vacations. He loves coming home, particularly for weddings and other special events, such as his favorite, the mid-May Magnolia Blossom Festival and World Championship Steak Cook-off, but after three or four days anywhere he's always ready to go back to his life on the pine-covered campus of AHDC.

Now, sadly, the very existence of this nation's remaining ICFs/MR as well as the happiness and well-being of Frank David, his friends, and the thousands of other severely mentally retarded citizens dependent on these institutions, is severely threatened by federally funded groups such as DD Councils and P&As. Led by ideologues who argue that these people's civil

rights were abused because they had no say in deciding their placement and by other groups who lobby to dismantle the whole system of institutional care, this movement has successfully closed down most large centers for the mentally ill and many ICFs/MR throughout the nation. They bring class action suits against the ICFs/MR using our loved ones' names as plaintiffs, with neither the consent nor even the notification of their legal guardians! They argue that these people, among the most vulnerable in America, would be better served in small community-based housing or at home.

They are wrong.

Citizens with less severe retardation can certainly live more independently,

but I assure that you Frank David, his fellow residents, and those all over this nation with similarly severe mental disability cannot. Imagine your toddler playing freely in the street whenever he or she pleases. Yes, your child would be exercising his or her civil right to, as

one zealot has said, "the dignity of

risk these people deserve." However, such "dignity of risk" might well cost your child, your loved one, my Frank David, and many others who are severely mentally retarded their lives.

A recent closure serves as a warning to us all. After a congregate care institution in Nebraska was ordered to "downsize" earlier this year, 16 of its residents were moved to smaller facilities and nursing homes. Within a few months, eight of those who had been moved from where they had lived so many years had died. I believe that while their physical needs were being met in the new places, their emotional needs and the jarring disruption of the change had robbed them of their will to live.

Every person with mental retardation has their own stories. Because many cannot articulate them on their own, it should be the mission of all of us who care for them to raise our voices to protest the dismantling of the very homes that protect them and provide for their wide range of mental and physical disabilities. Although small, community-based homes are fine for people with mild to moderate mental retardation, these homes into which many advocates want to crowd our family members with severe mental retardation cannot adequately protect them and serve their needs.

Thank you again for the chance to tell my son's story.

*First presented to the Rotary eClub of the Southwest USA*

*Frank David (was) too busy with his new friends to spend much time with us. We were thrilled.*

*Led by ideologues ...this movement has successfully closed down most large centers for the mentally ill and many ICFs/MR throughout the nation.*

rights were abused because they had no say in deciding

# Donor's Forum

## VOR Awareness Month 2009 a Success!

By Julie Huso, Executive Director

In October, VOR members, organizations and professionals from across the country planned activities to increase the awareness of VOR!!

The objective of this month long initiative is to let as many people as possible know about the important work of VOR, and the need for continued growth in members and revenue.

### Awareness Month Highlights

There were a number of participants all pursuing different awareness activities. I'll highlight just a few for you here.

The month was kicked off with a \$1000 gift from Jane and Bob Anthony! In addition to their personal gift, Jane is co-president of Parents & Associates of Northern Virginia Training Center (NVTC) and VOR Virginia State Coordinator, Jane also helped arrange the mailing of a letter to over 300 NVTC families and advocates that shared VOR's mission and accomplishments, and asked recipients to become VOR members. Jane also shared her letter with the other facility family groups in Virginia for their use.

VOR President Robin Sims put together an online Tupperware party that was promoted to VOR members and their family and friends. VOR received 15% of the proceeds from this event!

VOR's Florida State Coordinators Ed and Virginia Carraway and Connie Howard, with others, prepared a mailing to 500 families across Florida sharing information about VOR and VOR's statewide affiliate organization.

Other VOR members handed out VOR information at their meetings, arranged for VOR speakers, or included information on their newsletters.

Perhaps the most unique awareness activity was a recycling project with proceeds to benefit VOR!



Julie M. Huso

### From Georgia to Louisiana: My efforts in October

I was able to promote VOR Awareness by attending the East Central Georgia Family Council's Annual Picnic and Rally on the Gracewood campus. Georgia State Coordinator Ann Knighton, also a VOR board member, was my host and with her help we shared information about VOR with more than 100 family members, advocates and friends.

In October, thanks to help from Doris Pitre, VOR's Louisiana State Coordinator, I was able to tour all six ICFs/MR in her state, while also meeting with several families from Shreveport to New Orleans. Mary Kay Cowen, Chair of VOR's Membership Committee, invited me to attend the North Lake Friends and Family Day!

### Looking beyond October

VOR will celebrate VOR Awareness Month again in October 2010. But don't wait until then to help educate families and others about our important advocacy. VOR Awareness is something we must endeavor to do all year long. Please look for opportunities to share VOR's information and invite people to join as members. Whether you share VOR's website with one friend in need, or provide VOR information to many

families at your next, it all helps.

We face challenging times right now yet VOR's accomplishments such as H.R. 1255, Olmstead and the recent Ligas decision in Illinois clearly signify what a strong organization of members we have.

As 2009 nears its end, it is time to think positively about the future and to know VOR is 26 years strong and we will be here when you and your loved ones need us!!

We could not have accomplished the many things that we have if not for you!! **While you plan for your year end giving please remember your donations to VOR are critically important.**

**We cannot be SurviVOR's  
without you!!**

## VOR Contact Information

### Membership Dues/Contributions

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

### Executive Director

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

### Director of

#### Govt. Relations/Advocacy

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

### Washington, DC

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

President  
Robin Sims

Editor:  
Rochelle Hagel

**Ruth Attias: Perseverance defines mother's advocacy efforts** continued from page 7

With the help of her son, who is co-conservator (legal guardian) with Ruth, along with an experienced attorney, they have managed to have her annual placement hearing (called "Hop Hearings" in California) postponed until a Fairness Hearing can be held. The Fairness Hearing will decide whether Ruth wishes as Barbara's mother and conservator/legal guardian will be honored.

"I absolutely want Barbara to stay at Fairview," says Ruth. "They do amazing work for Barbara. She is happy there. She is safe. There's no place I would rather her be, and if Barbara could communicate, she'd agree."

Ruth has experienced firsthand the injustice of having a government agency (in this case, a Regional Center) challenge what she knows to be in the best interest of her daughter. She also knows that she is not alone.

"My story is, sadly, not unique," she remarked.

**H.R. 1255 – Justice for Families**

It is this injustice that has motivated Ruth, in her spare time, to help mobilize others to write Congress in support of H.R. 1255.

One Sunday morning in August, with the support of her Presbyterian church's *"I've visited her (CA Rep. Maxine Waters) office, I've called and I've written. I'll keep at it."*

Committee on Issues of Peace & Justice, Ruth set up a table with template letters and stamped envelopes to Congress seeking support for H.R. 1255. A large poster on an easel introduced people to Barbara, explaining her disabilities and showing her involved in a number of Fairview activities.

"On the spot, at least 30 people signed letters for us to mail to Congress," said Ruth. "Many other took the information home to study, along with

the stamped envelope and letter to sign and mail."

In November, she set up the same table at a Fairview Family and Friends meeting, where many more letters were sent.

She is proud of her efforts, which served to educate families and Congress, while also helping Barbara.

—Ruth Attias

As for her own Congresswoman, Rep. Maxine Waters, she is still waiting patiently for her to cosponsor H.R. 1255.

Well, not so patiently, but Ruth isn't giving up.

"I've visited her office, I've called and I've written," says Ruth. "I'll keep at it."

It is this perseverance that defines Ruth's advocacy work, all for Barbara and her peers.

"I'm definitely multi-tasking these days," she says.

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

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**Membership Categories:**

- Individual --- \$25
- Parents' Association --- \$150
- Professional Assoc./Corp. --- \$200

**An additional gift/pledge is enclosed for:**

\_\_\_ \$1,000 \_\_\_ \$500 \_\_\_ \$250 \_\_\_ \$100 \_\_\_ Other

A check made payable to VOR is enclosed.  
 Or please charge to my  VISA  Mastercard  Discover

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Expires: \_\_\_\_\_

Amount to charge: \_\_\_\_\_

Signature: \_\_\_\_\_

**Please check as appropriate:**  
 I am a new member  
 I am a current member and my records need to be updated (i.e. new address, name, phone, etc.). I have circled the changes needed on this form.  
 No changes are needed.

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