

VOR
the Voice
news and views of VOR supporters

Winter 2011



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Change

By Sybil Finken & Ann Knighton, Co-Presidents

Change.

It's a word that evokes emotion in all of us albeit different emotions: Excitement, trepidation, calm, and anxiety. As VOR's new Co-Presidents we can honestly say we experienced all of these emotions when it became apparent we would be called upon to lead VOR.

Upon our election, however, the emotions felt were humility, honor and determination - a determination to achieve VOR's mission by addressing the urgencies facing individuals with intellectual disabilities and their families.

Each of us has served VOR in a leadership capacity for many, many years. We have been active VOR members for a combined 27 years, and have served as State Coordinators and Board Members for many of these years.

As parents of adults with profound intellectual disabilities receiv-

ing high quality care in public ICFs/MR, we have been helped by VOR over the years in countless ways and we relate and empathize with families of all persons with intellectual disabilities who are struggling to access or maintain adequate supports - whether in their family homes, smaller settings, or in ICFs/MR.

In our states of Iowa (Sybil) and Georgia (Ann), we have dealt with DOJ threats (ongoing in Georgia), along with the usual threats by other advocacy groups who seek to dismantle any sort of specialized services in favor of their definition of "normal."

Each of us has faced (or are facing) the same urgencies and threats in our states as VOR's members and others have faced across the country. Throughout these challenges we have counted on VOR to be there, and we have not been let down.

Introducing Co-President Sybil Finken

Sybil has been an active VOR member since 1988, when she joined VOR founder, Marty Pratt, and others in Washington, D.C., to lobby for choice. She first joined the VOR board of directors in 2003 and was elected first vice president in 2008. In 2011, she served briefly as VOR's president following Robin Sims' passing. In October 2011, she was re-elected by VOR's Board to serve as co-president with Ann Knighton.

Sybil has also served on VOR's nominating committee, most recently as its Chair, and is VOR's long-time Iowa State Coordinator. She also served as president of the Glenwood (ICF/MR) Parent Family Association for 12 years. Sybil's son Seth has made his home on the campus of the Glenwood Resource Center since 1984.

Sybil and her husband Russ have been vocal advocates for the Resource Center and the level of care provided there. Sybil teaches elementary music in Glenwood, Iowa. In addition to Seth, the Finkens have three other children, Zachary, Luke and Carmen, a grandson Jackson and two granddaughters Mae Rae and Cleo.



Sybil Finken

VOR is there for you too.

As Ann once said, "We have carried the banner, stepped up to the plate, and risen to the issues, knowing that we have much work to do and many miles yet to go." VOR will walk these miles with you.

Thank you to Sandra Reeves for her service

Sandra Reeves resigned recently as VOR's President citing personal reasons. VOR is grateful for the time she dedicated to VOR.

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Who is VOR?

VOR is the only national advocacy organization supporting the right of individuals with intellectual disabilities and their families to choose from among a full spectrum of quality residential services and supports, including family home, small settings, and licensed facilities.

On The Cover:
Pencil drawing of Ann Knighton and her daughters.

Ann's story and biography are featured on pages 6-7.

The Gift of Being a Member!!



Julie M. Huso

For VOR, this time of year is always a busy, but festive, time. Like families across the country, VOR is preparing for the holidays while reflecting upon this last year. We have assisted many families, directly or indirectly, throughout the country. Here are just a few of our accomplishments in 2011:

■ In May, H.R. 2032 was reintroduced. This federal legislation, if passed, will restore individual and family decision-making rights when threatened by certain closure lawsuits (see page 9, for more information).

■ VOR has participated in a Med-

icaid Coalition in a collective effort to protect and preserve Medicaid, a life-sustaining program for people with ID/DD.

■ VOR's Legislative Committee launched a "DD Act Advocacy project." The DD Act (Developmental Disabilities Assistance and Bill of Rights Act) has not been reformed and reauthorized for more than a decade. Yet, Congress continues to ignore the harm of many DD Act program activities on people with ID/DD who need and chose ICF/MR care. VOR's advocacy is aimed at

We need your support. VOR relies on the support of friends like you to help to continue providing the services we offer. In these economic times your financial support is needed even more.

securing Congressional review and reform.

■ DOJ lost its case in Arkansas. The federal judge held that DOJ failed to prove its case against Conway ICF/MR and pointed to the satisfaction of families as a determining factor. VOR's late president Robin Sims provided expertise in the support of Conway.

■ In coalition with families of private ICF/MR families in Illinois, VOR helped secure a favorable settlement to the long-standing P&A *Ligas v. Miram* lawsuit. The settlement preserves choice while expanding community options.

■ As *Amicus*, VOR continues to support families of state operated ICFs/MR in a P&A case in Pennsylvania.

■ In 2011, VOR was present in nearly every state by providing current updates on legislative activity, grassroots advocacy, personal visits to family group meetings or conferences, and

spreading the word about the importance of the work we do at VOR.

VOR is available when you need us!

The work of VOR is never done and in fact our support and expert services are needed now more than ever. States have cut budgets or are facing budget cuts and reduced services. Anti-choice advocates, DD Act programs and DOJ continue their attacks. These groups make the assumption they know what is best for your loved ones. **CHOICE and family decision-making** need to be protected. VOR is the only national voice standing up for YOU.

It is with grateful hearts this holiday season that we thank you for your membership and donations to help support and maintain the only national advocacy organization that speaks out for a full continuum of care and choice! As you consider your year-end giving, please include VOR.

Thank you!

VOR Board of Directors

Ann Knighton (GA) Co-President
Sybil Finken (IA) Co-President
Bill Ryerson (NC), First Vice President
Barbara Cukierski (IL), Treasurer
David Swain (NV), Secretary
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Executive Director's Message

VOR

A Sibling's Perspective

Thoughts on a life with Jordy

By Carly Engels Johnston

Every parent believes their children are special. Whether they are exceptionally cute, smart, funny, talented in something like music or math, every parent strives to be proud of their children for their accomplishments and their character.

However, what do you do when your child is not any of these things? What do you say about a child who is not capable of achieving anything in life and whose biggest success is merely continuing to exist? This is what my family has faced.

I may have only been three years old when I became a big sister, but I understood right away that something was not right when my brother was born. There was not the great feeling of joy I expected to feel or see throughout my family. I knew something was very wrong. Instead of coming home with him, my parents instead disappeared from my life. They took him all over trying to figure out why this happened, what happened exactly and what could be done to help him.

Luckily, I had a strong family support system so I stayed with both sets of grandparents and everyone tried to make my life as easy as possible. When someone finally explained to me that my brother was profoundly retarded and severely handicapped, I knew that no one in my family's life would ever be the same.

I remember a lot of crying. I remember a lot of people coming through our home to care for my brother. I remember the day my parents realized it would be impossible to for him to live at home and he would need to reside at a facility where there were other people like him. And, I remember the day he moved there and all the times I would leave school early so we could drive the three hours to see him.

I knew that in my life, this was not enough. Selfish as it was, I wanted a sibling, a real sibling. Someone I could play with and talk to. Even though I was only four, then five, I passionately argued for my parent's to try again, completely unaware of how they must have felt and the risks that might be involved.

When my sister was born, loud and healthy, I knew there was a big feeling of relief. It was palpable. Yet, this is where things became difficult for me. My sister always viewed my brother as a normal part of our family. She had no problem interacting with him or visiting him. She was born into the situation and when she was very little, she assumed everyone had a brother like ours.

When I was in grade school I was teased about my brother, like being a kid isn't hard enough and kids don't already have a plethora of things to pick on someone about already. The word retarded was thrown around in every

conceivable hurtful context. At that age, no one understands that, sometimes, bad things happen to good people for no reason. My parents did not deserve this. It was not God punishing them and it was not the result of anything they did or did not do.

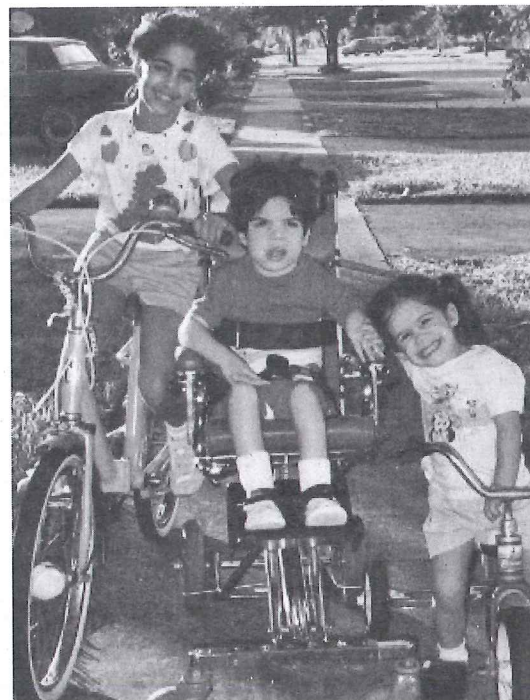
Even when I got older, unconsciously, I did not bring up the subject of my brother. It was not as if the topic came up often either. There were many times when people who had known me a long time did not even know I had a brother. I was not ashamed, but merely did not think to make it something to be known for.

Subconsciously, watching my parents fight for funds to keep my brother alive and issues related to his care propelled me to study health law in law school. When my brother passed away the year after I graduated law school,

I will not lie, I felt a weight had been lifted off. As much as I loved my brother for who he was, I admit I did not like what he was. Again, I know he could not help it, but I felt little connection to him and so when he passed I felt like he was probably more at peace in that moment than he probably had ever been, though I am sure he was not ever conscious of it.

I do realize that after he died I was more adept at talking about him. I did bring up the subject of him more voluntarily and my tribute to him has been to continue the activism work my parents advocated for and carried through while he was alive. I honor his memory by trying to make sure other families have access to the same quality of care my brother had during his short lifetime.

Many people applaud my efforts because I have continued to do this after he died. The truth is, it became easier after his passing because I am no longer as connected to it; I have some distance. Since I am a more rational than



Carly, Jordy and Margo Engels 1989

***I honor his memory
by trying to make sure other families
have access to the same quality of care
my brother had during his short lifetime.***

Continued on page 5

Three Siblings' Perspective

By Maureen Durkan, Anne Pichette and Mary Durkan

Our "little sister" Sharon is the youngest of seven children, four girls and three boys. She is the light of our lives and has taught us about love, compassion and giving to others. She does not know what hate is; she is innocent, sweet and kind.

Sharon's mental age is probably somewhere between two and three. As you can see in the picture of her, she loves stuffed toys and dolls.

She normally carries around two or three at a time; her Dora doll is her favorite. Sharon was brain damaged at birth and lived at home until she was eight years old. She was quite active and kept us all very busy. She liked to go off exploring, sometimes in the middle of the night and at other times she would go into the neighbor's homes looking for toys and food.

Our parents wanted to keep Sharon at home, but she took up most all of their time and they had six other children to

raise. Sharon needed 24/7 supervision; understandably, her high care needs were stressing the family out. We suffered from sleep deprivation in those days.

Sharon had one out-of-home placement before she went to live at Fircrest ICF/MR ("Residential Habilitation Center" (RHC)), where she has been since 1974. At that time, some of us kids wondered if Fircrest was the best place for her or not.

Our parents told us that the staff at Fircrest "took better care of Sharon than we could" and that Sharon was learning new things every day, had caregivers/professional staff that were experts in understanding her needs, and she had a large safe campus to roam on.

Our mom admitted that Fircrest may not be perfect (that was 1974) but she told us that it was our duty to work to

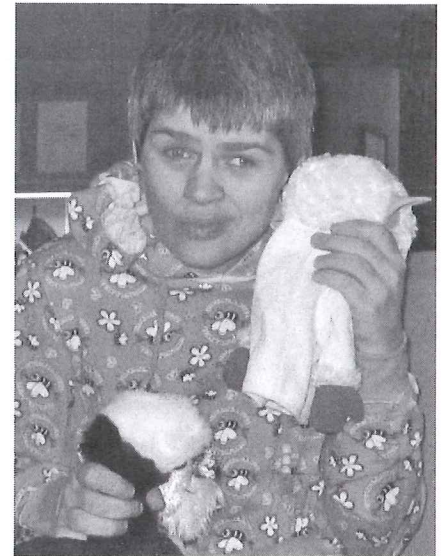
make sure it was. She told us that people with developmental disabilities were not highly regarded in our society and it was our responsibility to work to change that. Mom was a great role model; she volunteered at Fircrest regularly in the 70's and 80's and was always busy advocating for people with developmental disabilities.

Our parents were very devoted to Sharon and visited her often at Fircrest to make sure she had what she needed.

Now it is our turn.

Our father passed away in 2003 and our mom is now 90 years old. The three of us—her sisters—care for Sharon. We take turns visiting Sharon every weekend and taking her on outings, attend her annual IHP's, and go to the Friends of Fircrest meetings.

None of us will ever forget what a challenge it is to care for our sister who is profoundly developmentally disabled. We don't want other individuals, or families, to suffer without proper services for their loved ones. Our state RHCs are a godsend. We need them as part of our continuum of care for all citizens with developmental disabilities to be able to access. We advocate for these services all the time with VOR, Friends of Fircrest and our state organization ActionDD <http://www.actiondd.org/>



Life with Jordy continued from page 4

emotional person, I sometimes still have trouble justifying the argument of allocating money to people who do not really actively benefit society, but then I remind myself that they did not wish this upon themselves and therefore should be not penalized for their disposition. It is society's obligation to take care of everyone including the sick, the weak, the infirm and the imperfect – a categorical imperative if you will.

I would not say I am stronger because of my experience. I would say my parents are the stronger souls. I would not say I am a better person because of the work I do. I would leave that title to the caregivers who work with

retarded and handicapped every day. I would not call myself lucky because I learned tolerance or empathy or understanding. I may have learned these things, but I learned them the hard way.

In the end, I am just another person who was faced with an extraordinary experience, not of the good kind. I am sure if you ask my sister, she will have a very different account of life with Jordy. The same can be said for my parent's perspective or people who know us. I can only speak for myself. My voice is the one that rings clearest in my head and this is the experience I take with me when I face the world and the future.

Coming next issue: Marlo Engels' perspective on her "life with Jordy."

VOR

Excerpts From A Diary

The Augusta Chronicle, 1980

By Ann S. Knighton

12/5/72. Today Erica went to Gracewood [ICF/MR]. I wish I were dead; then I would not have to think about it.

12/8/72. I don't know if I want to talk about Erica. I do know that I haven't felt relieved with her gone. It's like hoping someone who is terminally ill will soon die, but then not feeling relieved after the death.

12/11/72. I am grateful that my job as a biology and chemistry teacher at Richmond Academy demands much of my time. My whole day went well; as a matter of fact, it was salvation for me. The thought of coming home and not having Erica here is cause for me to worry. Anxiety makes my stomach quiver and I think, "What is next?"

12/13/72. I wonder what is going to happen today? It is Wednesday and I still will not get to see Erica today as I have an evening meeting I must attend.

I still remember the happy look on Erica's face when she came out to see her sister, Stephanie and me last night. Dear Stephanie; how hard this is for her. She tried to take Erica home by refusing to let go of her hand last night.

I still have so many questions going through my mind. Why did this happen to me? Why does Erica have to be retarded? And if retarded, why a chromosome anomaly which is the most severe kind? Why are my ideas so different from those of my family? Emotionally, I know they do care. Why must I have the extra burden of divorce? Why must I be two people at once, both stay home and work? Why, why, why?

Same Day **10:30 P.M.** Every time I attend these meetings on mental retardation, I always want to cry. The meetings are very well organized and everyone is so kind and understanding. Does anyone else feel as weepy as I do or am I all alone in my feelings? Please tell me, someone! Why do these meetings make me so emotional even though I enjoy them? Are they good for me?

Same Day **1:00 A.M.** I cried. I finally cried! For five years I have wanted to really bawl, and yell, and yell. I cry for Erica, for me, for my divorce, for the attitude of my family towards Erica. Crying is some relief. I must sleep now.

12/14/72. I keep thinking, "If I'm not careful. I will wake Erica." Then I remember that Erica is not here to be awakened.

I find myself doing things to protect Erica: putting the scissors up immediately after using them; putting up all medicine; putting a hot iron in a safe place; turning handles of pots inward on the stove.

Later Same Day: My attitude about Erica and my family's attitude are totally different. I find this hard to handle. It is painful.

12/15/72 12:30 P.M. While scooping up some very brittle magnesium oxide from its container for one of my chemistry classes, the thought passed through my mind, "Erica is retarded; she will never be normal. Erica is at Gracewood." An emptiness seemed to engulf me, my stomach quivered and my chest became tight. But I quickly turned to my class and continued issuing chemicals in their experiment.

Today Stephanie spent some time with my mother and father. It is right that Stephanie be with her grandparents. She must not be deprived of a normal childhood. My parents probably feel that I need some time to myself since Erica is not at home temporarily. I must not allow myself to become dependent over Stephanie. I love both my children very much, but still I am haunted by the indecision about Erica. Is Gracewood truly the best place for her? I must remind myself of Jeremiah 32:17. "Ah! Lord God Thou didst build the Heavens and the earth by Thy great power and stretched out arm, and there is nothing too hard for Thee."

I cannot afford to mope. I have work to do. I am going into the kitchen to wash my dishes, remove the papers from my table and think about getting and decorating a tree for the girls.

12/16/72. Another Day. Another Time. Another Place. Stephanie went to spend the day with Grandy and Grandma. I went with a friend to Gracewood to see Erica. I pinned some orange

barrettes in her hair. We stayed at Shoney's on the way home. The cake was delicious. It was a good day.

12/19/72. Today it was sixteen days. I had to be at school at 7:00. I would not start so Stephanie could go to school. I was glad for once to be at Gracewood. It usually takes 15 minutes to walk but it was so hard to walk fast!

12/21/72. This is a rainy day. I am very much except sleep. Mrs. Gracewood to see if I were going to see Erica tomorrow. I assured her I would.

I have had sixteen days to think about Erica; sixteen days to do my chores, to think, to clean my home, to live my life. But I have done only my chores. All I have been able to do is think. Perhaps with Erica home and my family together I can find a future of my life and the future focus.

Epilogue (written by Erica)

It has been eight years since my temporary visit to Gracewood. I have had many sleepless nights and made many decisions. I did not send her home. I have learned that I love her heart and mind; she is part of me. It may be. It is fortunate for her that she accepted at Gracewood because for all involved. She is severely mentally, but physically healthy. It is painful; it hurts; it always has. The fact that Erica is old makes things any easier. However, I must deal with the total matter. At last I am free to see Erica when I want. She will come home several times during the year.

The reality of my life is still the same. My relationship together with her is the same. We talk a lot; we do much together. We laugh, we sing, we dance. We are together. Stephanie is now sixteen. She is a typical happy teenager.

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Once more the Christmas Holidays approach and the time before Christmas when so much has to be done, Stephanie comes home all excited about some school affair. "Mama, are you listening to me?" No, Stephanie," I reply honestly, "I have been thinking about Erica." Her expression changes quickly. She comes over to me and puts her arm around my shoulders.

"Will Erica be home for Christmas again this year?" I nod and shortly we are sitting at the kitchen table eating our dinner and planning what we shall do for Erica at Christmas.

"Mother, can try some new toys again this year? There probably are some that make a noise that she will like?" I look at Stephanie and see the eager expression on her face and nod my head. Each year, it seems, we try something different hoping she will respond, but it always ends up with her old favorites, the Mattel "the Farmer Says" and the Fisher Price Telephone. Still, maybe this year will be different. Stephanie smiles, "I'm sure they have lots of new things at the Malls. I'll look; I know what she'll like." She gets up and starts to leave the room then turns back.

"Mama, can we have more lights on the tree this year and maybe a bigger tree?" She looks at me; again I nod. Is this for Erica or Stephanie?

She comes back and gives me a quick kiss. We both know Erica's reaction to the tree. But as always we look forward to seeing her smile at the Christmas Tree lights after we have turned them on at least five times to get her attention.

I listen as Stephanie closes the door to her room and know that I truly look forward to having Erica home to play with her same noisy toys. I look forward to seeing her step all over the unwrapped packages to take a seat in the midst of them and chew on her favorite towel. I look forward to holding her and having both girls together for Christmas. Outside the early winter reminds me I must finish my lists and start the many necessary chores to have things in order, because it is Christmas once again.

Stephanie Knighton graduated with a degree in English and is an accomplished writer living in Augusta. She and Ann see each other as often as possible.



Stephanie, Erica & Ann Knighton

Ann S. Knighton is a native of Augusta, Georgia. She graduated from Paine College with a BA in Natural Science with emphasis in Chemistry in 1959; and from Augusta State University in Sociology in 2000 (Dean's list). From 1968 – 1995, she was a science and chemistry teacher at the Academy of Richmond County. She is currently employed by the Augusta Recreation & Parks Department (Sand Hills Community Center), where she organizes senior activities. During her many years as a teacher, Ann was the president of the local teacher's organization (1984) and on the board of the state teacher's organization (1988), experiences which first brought her to Washington, D.C.

Throughout Erica's life, Ann, has served on various boards of organizations working for the betterment of people with developmental disabilities, including as President of the Family Council for East Central Georgia (Gracewood State School and Hospital). For her volunteer services, Ann has received many awards, including Woman of the Year (2001, First Day Spring Baptist Church; 2002, National Association of University Women) and Citizen of the Year (2002, Georgia Social Workers Association).

See Voice Award on page 10

VOR

Louisiana mom fights back, wins

"Deciding to fight is what saved the day," said Jason Senegal, an attorney with Acadiana Legal Services in Lafayette, Louisiana, who represented Dwayne, a resident of Pinecrest ICF/MR. His case was brought to Mr. Senegal's attention by Dwayne's mother, Cinthy Broussard, who sought to challenge the State's attempt to move her son from Pinecrest.

Like every resident in Louisiana's state ICFs/MR, Dwayne underwent a new assessment to determine his level of support needs. Implemented first for the state's home and community-based waiver, the state began using an adaptation of the Supports Intensity Scale (SIS), a national model, for assessing the care needs of ICF/MR residents.

The State's goal was to identify residents with fewer needs and target them for transfer, going so far as to decrease the ICF/MR budget by 20% before the assessments were even started.

Dwayne was among those individuals who were targeted for transition. His mother strongly disagreed, noting that even the smallest changes brought about dangerous behaviors, a factor the assessment process did not consider.

After failed appeals, with VOR's help, she requested a "Medicaid Fair Hearing," the last administrative appeal; after that she would have to take her concerns to a court of law. She won – on a technicality. The technicality, how-

ever, has brought hope to families. The administrative judge found that Dwayne's case was not "ripe" for consideration because the State did not actually require he be moved.

"What we learned was that the State could not legally require Dwayne to move from Pinecrest, his home," said Mr. Senegal, who represented Dwayne at the fair hearing. Despite public statements to the contrary and a budget which counted on transitions, Louisiana law and regulation relating SIS assessments only served to encourage – not force – transitions.

"When I first learned about Cinthy's fight, I called her a 'trailblazer,'" said Tamie Hopp, VOR's director of government affairs and advocacy, who provided advocacy assistance to Cinthy and Dwayne. "The administrative appeal process associated with the SIS 'level of need' finding was complex and not tested. She had managed to work her way through most of the steps on her own. Little did I realize, however, that Cinthy's decision to fight would uncover something so meaningful – the State does not have the authority to require transfers based on Level of Need finding alone. That's trailblazing."

VOR is now working to help get the word out. Affected families are preparing to fight back, feeling empowered by Cinthy and Dwayne's victory.

Pennsylvania: Families appeal settlement

Families of several state-operated ICF/MR residents have filed a notice of appeal in an action they fear will ultimately result in the closure of state-operated ICFs/MR in Pennsylvania. On September 2, in spite of objection letters from more than 100 families, a federal judge approved a settlement agreement in *Benjamin v. DPW*. As many of the objection letters recognized, the settlement will result in the displacement of state center residents from their long time, specialized care homes. Even the judge acknowledged that the "assessment protocol . . . may imply an unintended bias towards community placement," however, he still approved it. Of particular concern is the settlement provision that allows an individual's silence to mean acceptance with regard to community place-

ment ("does not oppose"). In Pennsylvania, a significant percentage of individuals are not able to communicate in any way due to their severe and profound intellectual disabilities, and many of these individuals do not have families. The appeal will be heard later this year. VOR will participate as *Amicus Curiae* ("friend of the court") in support of the ICF/MR residents and their families.

Alabama: Family files lawsuit to save Partlow

Louise McRae filed a lawsuit against the Alabama Department of Mental Health over its plans to close Partlow no later than Nov. 30 and move eligible residents of the facility into community homes. The state announced Partlow's closing in March. Partlow, the only state-run facility for people with developmental disabili-

ties, has been home to McRae's 61-year-old son, Mike, since 1973. She said she does not want to move him to a community-based facility. She contends that only the Legislature has the authority to close Partlow, and that the State's decision to close the facility constitutes impermissible rulemaking. McRae's lawsuit also contends that the law gives her the right to choose either a state facility or a community-based home for her son.

Alabama responded with a motion to dismiss arguing that the state has the authority to manage facilities and an obligation to seek the best care for its residents, which it believes is in community-based homes. In a ruling without any explanation, the court granted the motion to dismiss. An appeal is being considered.

Patrons of Partlow has set up a website dedicated to its fight to save Partlow at www.patronsofpartlow.org.

VOR's DD Act Advocacy Project

For more than 2 decades VOR has led efforts to reform the DD Act. In 1993, VOR secured the "primary decisionmaking language" in law and in 2000 that language was strengthened to recognize residential choice.

DD Act programs have persisted, however, despite the DD Act mandate and Olmstead requirements.

With each June Initiative, VOR has called on Congress to reform the DD Act, sharing examples of the DD Act's attacks on the ICF/MR option and their human impact.

This fall, VOR launched its DD Act Advocacy Project in an effort to encourage regular constituent contact with key Members of Congress, especially Members of the House Energy and Commerce (E&C) Committee.

Rebecca Underwood, VOR Legislative Committee member, is coordinating this effort. If your Congressperson serves on the E&C Committee, or you would like to help, please feel free to contact Tamie Hopp at thopp@vor.net; 877-399-4867; or Rebecca Underwood at krr.underwood@gmail.com; 920-474-4201.

New! E-advocacy training program

VOR is offering a free (to members) three month e-advocacy grassroots training program which will cover general effective advocacy principles. Materials will be provided by Stephanie Vance of Advocacy Associates and will be relevant to your state and national advocacy efforts.

Does VOR have your email address?

If not, please send your email address to info@vor.net. In addition to the upcoming e-advocacy training program you will also receive VOR's Weekly E-Mail Update publication, another benefit of VOR membership.

H.R. 2032: Still gaining ground

H.R. 2032, a bill which seeks to restore the decision-making rights of ICF/MR residents and their family members/legal guardians, now has 65 cosponsors. Moreover, H.R. 2032 was recently referred to the House Judiciary Committee's Constitution Subcommittee. A growing number of cosponsors and a subcommittee referral (a necessary step toward passage) signals real progress!

We need the help of every VOR member to keep this momentum going strong. Here's how you can help:

1. Ask the Judiciary or Health staff for your Congressperson to contact **Holt Lackey**, Counsel to House Judiciary Committee Chairman Lamar Smith, in support of a hearing on H.R. 2032;

2. Ask that your Congressperson contact **Chairman Smith** and **Subcommittee Chairman Trent Franks** directly in support of a hearing on H.R. 2032; and

3. Cosponsor H.R. 2032!

Details, including additional background about H.R. 2032, a template letter and Congressional contact information is available here

<http://www.vor.net/legislative-voice/action-alerts>.

Questions? Contact Tamie Hopp, VOR's Director of Government Affairs and Advocacy at thopp@vor.net or 877-399-4867. THANK YOU!

Leader of Iowa P&A advocacy group forced out

The head of Iowa's P&A advocacy group for the disabled, Disability Rights Iowa, has been forced out, one month after accusing Gov. Terry Branstad of failing to protect some of Iowa's most vulnerable citizens. Sylvia Piper, who headed Disability Rights Iowa for the past 11 years, was fired by the organization's board of directors recently.

Although Disability Rights Iowa claims the firing was due to agency finances, the move came six weeks after Piper published a scathing open letter to Gov. Branstad. Reportedly, the Governor has considered making Disability Rights an agency of state government. Disability Rights has expressed concern that such a move would effectively neuter the agency and make it harder to sue the state or call for the closure of state ICFs/MR, as it has in the past.

VOR offers comment to "Super Committee"

The Congressional Joint Select Committee on Deficit Reduction ("Super Committee") is mandated to consider ways reduce the deficit by at least \$1.5 trillion over the next ten years and present its plan to Congress on December 2. In October, VOR submitted comments raising concerns regarding the use of DD Act program funding to eliminate ICFs/MR.

To comment, visit <http://www.deficitreduction.gov>.

VOR launches a petition, calls for reform for system-wide crisis

Waiting lists, service cuts, lack of oversight and abuse rates point to a crisis in the care system serving people with intellectual and developmental disabilities (ID/DD).

Calling on the Obama Administration to address this crisis and asking all advocates to set aside biases and work together on a solution in support of people with ID/DD, VOR has posted a petition on the White House's "We the People" Petition website.

Our petition is enjoying wide circulation and signatures are growing, but we need your help. By Dec. 1, please go to <http://wh.gov/bBY> to sign the petition (see also, www.vor.net). Only online signatures are permitted for this petition.

Thank you for your support!

The logo for VOR (Volunteers of America) features the letters 'V' and 'R' in a large, serif font. Between the two letters is a stylized graphic consisting of three concentric, overlapping arcs that resemble a rising sun or a stylized 'O'.

Artistic integration at ICFs/MR

Florida: Tachachale residents perform at the Hippodrome

On June 20, Individuals with intellectual disabilities who call Tachachale ICF/MR home showed off their creative capabilities with dance routines and musical blues acts at the Hippodrome State Theatre. With influences from the Temptations, Michael Jackson, and the movie Grease, these individuals presented "The Time of Your Life," their first performance in a public venue. The dance troupe, Controlled Chaos, and a musical duo, the Blues Brothers, joined fellow residents in an hour long public performance.

"This is the first time ICF/MR residents were brought together to headline in a community production," said Julie Waldman, who choreographed the event. "This is a whole new direction for us. We're excited to break new ground."

Tachachale is a state operated ICF/MR located in Gainesville, Florida. For more information: Julie Waldman, (352)955-5757.

Voice Award continued from page 7

Ann has been active in VOR for many years, serving first as its Georgia State Coordinator, joining the VOR Board in 2006, and then serving as VOR's second vice president for several years. She was VOR's 2011 Voice Award recipient in recognition of her dedicated advocacy for nearly 50 years. In October 2011, she was elected by the VOR Board of Directors to serve as co-president, with Sybil Finken.

The Voice Award

Ann S. Knighton

For the lifetime of many; for Erica's lifetime,

Your generous, caring, and deep commitments to improving the lives of your daughter and her peers with mental retardation,

Have been pivotal to the successful pursuit of VOR's mission to enhance care and increase choice for all people.

You have "carried the banner, stepped up to the plate, and risen to the issues, knowing that we have much work to do and many miles yet to go."

We are grateful to you for your leadership and sustained contributions to our shared advocacy.

**Dedication on Ann's Voice Award
presented at VOR Annual Conference June 11, 2011**

Hunterdon Developmental Center's Fine Arts Program

Hunterdon, a state-operated ICF/MR, encourages its residents to experience the arts in a therapeutic atmosphere while enhancing self-esteem and personal growth. The Hunterdon Fine Arts Program focuses on the artistic process involved – not the finished product. Classes allow for experimentation and the freedom to create beautiful and unique art works. Independence and creativity are developed through a ceramics, painting, drawing, sculpture, jewelry making and more. The resulting designs are incorporated into t-shirts, wrapping paper, calendars, jewelry, and stationary. Individual portfolios are maintained for each artist from which artwork is selected for exhibition or sale on campus, in local shops, libraries, airports, cafes, art galleries, and corporations.

*Thank you, VOR, for teaching me
how to advocate and for being effective
for people who can't speak
for themselves!*

-Linda Lotzi



Robin Sims, former VOR president, seated, presents The Voice Award to Ann Knighton.

Looking for State News?

Go To:

www.VOR.net/news/state-news

While you're there, make it your homepage!

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Consider Giving the Gift of a VOR Membership

It is critically important to involve your family members and share with them all the hard work you do for VOR.

If you have children, brothers, sisters or other family members who are not VOR members, the gift of a VOR membership gives them the opportunity to see firsthand all the wonderful work we do and why it is so important to support VOR.

Please provide them with the opportunity to see firsthand how we work to protect the rights of their loved ones!

Please see page 11 for a VOR membership form, which you can use for your gift membership, or visit us at: **www.vor.net/online-membership-form**

VOR will send a personal note to all "giftees" to inform them of your generosity.

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
@ <http://www.vor.net/online-membership-form>

**Thank you for your dues and
year-end contributions!**

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Telephone number(s) _____

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☐ My contact information has changed.

I would like to make a gift in ☐ honor ☐ memory of:

Membership Categories

- ☐ Individual --- \$40
☐ Family/Parents' Association --- \$200
☐ Professional Assoc./Corp. --- \$250

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City _____ State _____ Zip _____

Checks made payable to VOR, or by credit card:

☐ Visa ☐ MasterCard ☐ Discover

Card Number: _____ Expires: _____

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Amount to charge: \$ _____ Signature: _____

I would like to make an additional year-end gift to support future efforts of VOR. An additional gift is enclosed for:
☐ \$5,000 ☐ \$1,000 ☐ \$500 ☐ \$250 ☐ \$100 Other \$ _____

If the minimum dues requirement poses a financial difficulty, please contact our office in confidence (877-399-4867). It is in our best interest that you receive VOR's information, so please call if \$40 per year poses a financial hardship. Dec11NL



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Tributes

**Thank you to all of the individuals
who requested or gave donations
to VOR in honor of someone special,
or in memory of a loved one.
For those of you who have lost
someone special, please accept
our deepest sympathy.**

IN MEMORY

**Robin Sims
Patsy Eaves
Imogene Lemcke**

IN HONOR

**Michael Scully
Cheryl Sorter**

Make a Lasting Impact With a Will Bequest

Will bequests are the most popular and personal way to make a difference beyond your lifetime. A bequest is a charitable gift of property to be delivered at the donor's death. You can create a will bequest simply by directing in your will that your interest in certain money or property be transferred from your estate to VOR.

Why?

- Charitable bequests present an excellent way to pass on assets that may otherwise be substantially taxed.
- The donor's estate may be entitled to an estate tax charitable deduction for the full, fair market value of the bequest.
- You would be supporting a charitable organization that you believe in and passing on a legacy.

If you would like additional information on how to leave a bequest to VOR please contact Julie Huso, executive director, 605-370-4652 or jhuso@vor.net.