



REMEMBERING ROBIN SIMS OCTOBER 23, 1953 - JUNE 23, 2011

THIS ISSUE OF *THE VOICE* IS DEDICATED TO ONE OF OUR GREAT VOICES

THANK YOU, ROBIN, FOR YOUR PERSISTENCE, SPIRIT AND EXAMPLE

Also Inside

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Called again to serve

By Sandra Reeves, President

The first time I attended a VOR Meeting in 2000, I sat in awe of the passionate and knowledgeable members and staff. Members easily bandied about information on various bills and statutes, as the whys and wherefores of our discussions with representatives and their staffs were reviewed. Along with advocacy issues, we discussed which members of Congress would support or object to VOR's issues.

Becoming president of this esteemed organization was as likely in my mind as a trip to the moon. Yet, here I am. Thank you one and all for this opportunity to continue to learn how to influence our government.

Who I am...

...just so you know little bit about me and why I advocate. My first born, my son Reuben, has intellectual and developmental disabilities (ID/DD). As a young mother in the 1960's, I knew only that he had epilepsy and was not achieving his developmental milestones. I had a daughter two years after his birth and another daughter seven years later. When he was six years old it became necessary to find a private facility where he could be cared for safely.

Eventually, he qualified to live in a "state school" (an ICF/MR). I went to work to pay for his care and continued to work first in the medical field and eventually as a certified financial planner in the financial services industry. While

working, I did what I could for my son while raising and supporting my family, but always wishing I had more time to do more than attend meetings and visit him. My time to do more came unexpectedly in 2006 when I was asked to run for president of the Family and Friends Association where he has lived for 37 years.

Now, with the passing of Robin Sims, I am, sadly and unexpectedly, called again to serve. I am a firm be-

*I am a firm believer
"that the Lord never
gives you more than you
can handle."*

liever "that the Lord never gives you more than you can handle." I hope to help make VOR known to not

only those of us who advocate for our loved ones but to the thousands of families who have family members with ID/DD who have never heard about us. I hope to inform new families facing the same unknown, uncertain future I faced 53 years ago about the many choices they have for quality care for their loved one, including ICFs/MR. I hope to educate families and counselors

*...our loved ones
deserve quality choices
and no one option fits all.*

that ICFs are often wonderful places that can provide a quality and

breadth of services not available elsewhere. I hope to open eyes and minds to the understanding that our loved ones deserve quality choices and no one option fits all.

I will need your help and support. Ideas of what you can do to help achieve these goals and more will be forthcoming in future newsletters and communications. I will be soliciting your help and your ideas to make VOR available to many, many more people with ID/DD and their families.



Sandra Reeves

REMEMBER
YOUR DONATIONS GIVE VOR
THE ABILITY TO SUCCEED

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VOR MISSION STATEMENT

The mission of VOR is to unite in advocacy, educate and assist families, organizations, public officials, and individuals concerned with the quality of life and choice for persons with mental retardation within residential options including home, community-based options and facility-based care.

On The Cover:
Robin Sims

Photo by: Ozzie (rvoiipphoto.com)

Saying "Goodbye"



Photo by: Ozzie (vooliipphoto.com)

A Tribute to Robin Sims

October 23, 1953 - June 23, 2011

Robin Sims, VOR's past president, passed away June 23, 2011, after a long battle with cancer. The following is our tribute to this remarkable leader, friend, mentor, and advocate.

"Resolve is what brings us back every year and what keeps us going as advocates day in and day out, even against the odds. If not us, who? Our resolve asks to the immediacy of the need and our unending actions to meet our daily challenges."

This statement was part of Robin's VOR President's Message at the 2011 VOR Annual Conference in June, just a week before her passing. Robin had been VOR's president since 2008 and "resolve" describes so well her every action on behalf of individuals with intellectual and developmental disabilities (ID/DD) and their families.

VOR represents a necessary voice: Families. VOR is the only national advocacy organization for people with ID/DD that stands up for the right of individuals and their families to choose from a full array of service options to meet very diverse needs (www.vor.net). VOR respects choice and embraces the individual and family voices as primary.

As the mother of two children with developmental disabilities, Robin brought to VOR a passion for our mis-

sion that is really only felt by families whose motivation is personal. Advocating and leading alongside mothers, fathers, sisters, brothers and other close relatives, she motivated others by example and reminded anyone who would listen: "If not us, who?"

Robin was not easily deterred in the face of injustice. From the Halls of Congress to living rooms, Robin's advocacy meant the difference between desolation and salvation for countless individuals and their families.

Thank you for allowing me to represent you. I have learned so much and have worked so hard to be your presence on our national issues. I hope I have made you proud.

Robin Sims, 6/11/11

Perhaps Robin's greatest gift to our advocacy movement is her legacy. She has left us with the wisdom, the energy, and the knowledge to know we can carry on – that we must carry on. Her legacy will not fill the hole in our hearts, but will sustain our advocacy on behalf of all people with ID/DD.

The Robin Sims Memorial Fund: Sustaining Robin's legacy

To honor Robin's memory and to sustain her advocacy legacy, her family has established the Robin Sims Memorial Fund. Her memorial fund will make contributions to organizations dedicated to advocacy on behalf of people with intellectual and developmental disabilities. Please consider a contribution:

Robin Sims Memorial Fund
356 Jarome St.
Brick, NJ 08724

On the web:

Video tributes to Robin Sims

<http://youtu.be/bcEInf2tKxI>

(her brother's tribute)

<http://youtu.be/L6HDA6kUIyc>

(NJ Legislators' tribute)

Remembering a tireless advocate

Robin's legacy will carry on through others and I just know the intellectually disabled benefited from all her efforts and as a result, we are in a better place.

James E., Texas

Her energy, forthrightness, sincerity, and commitment are a beacon and an example for me and all who knew her. We can aim to walk in her footsteps, but they are huge. I miss her terribly.

Jane A., Virginia

Robin's kindness, fierce determination and truly indomitable spirit triumphed and soared in spite of the physical challenges her illness imposed. . . After a long day of conference activities, punctuated by an impassioned and inspiring speech she had made earlier in the day, Robin's excitement for the work we were all doing was still palpable. Her spirit was not only extraordinary, but seemingly inexhaustible . . . She will continue to serve as a power of example to us all. Her spirit will live on in all the good works that VOR surely will continue to do.

Hugo and Cristy D., New York

Read more on page 12

VOR

VOR Washington Initiative: Bringing choice message to Congress

For more than 15 years, VOR has hosted a Washington Initiative, providing VOR members with the unique and highly effective opportunity of bringing their stories and our shared message directly to Congress. This year's annual event was the week of June 13, with good timing on our side. Just a few weeks earlier, on May 26, Reps. Barney Frank (D-MA), Bob Goodlatte (R-VA), and Debbie Wasserman Schultz (D-FL), introduced H.R. 2032, legislation that would help restore individual and family decision-making rights in federally-funded class action lawsuits, and in DOJ actions, involving ICFs/MR. Then, on June 8, a federal judge validated the need for H.R. 2032 by finding in favor residential choice and family decision-making, and rejecting DOJ claims (see p. 9 for related article).

Protection for your rights: The new and improved H.R. 2032

H.R. 2032, like last year's legislation, provides residents of ICFs/MR, and where appointed, their legal guardians, the opportunity to receive notice and opt out of federally-funded class action lawsuits involving their homes. H.R. 2032 also includes a provision in response to recent DOJ threats. H.R. 2032 requires that DOJ consult with families during an investigation, and provides for a right of intervention if a lawsuit is filed.

At press time, H.R. 2032 boasts 47 cosponsors. The Initiative – those face-to-face meetings – absolutely helped enlist cosponsors, but so did contacts from “back home.” YOUR VOICE MATTERS. More than 10,000 bills are introduced each Congressional session; less than 5% pass. Constituent communication – in person and in writing – is the most ef-

fective way (in some offices, the only way) to take an elected official from information to action (cosponsoring H.R. 2032). Please do you your part and make your calls to your U.S. Representative today, and then follow up regularly. Persistence pays. (See “On the Web,” below, for advocacy resources.)

VOR calls on Congress to preserve Medicaid

As this newsletter goes to press, the debt ceiling deadline of August 2 is rapidly approaching. The resulting budget negotiations are difficult. Central to those negotiations are proposals that would fundamentally change Social Security, Medicare, and Medicaid. Democrats and Republicans disagree on whether to do a short-term plan or a more comprehensive, longer-term deficit reduction

plan. For people with intellectual and developmental disabilities (ID/DD), Medicaid is often their only resource for accessing health care, assistance and long-term care (e.g., ICFs/MR, benefit provided at the option of each state). In June, VOR reminded Congress that for these Americans the Medicaid program ensures maximum independence and daily happiness, and that proposals to cut Medicaid will not save money, but instead shift the financial burden on states, localities, providers and families, and jeopardizing coverage for millions of beneficiaries. Revenues will also be lost due to its impact on employment and business activity, particularly in the health and disability services sectors. VOR called on Congress to protect and preserve Medicaid, a life-sustaining program for people with ID/DD.

On the Web

Congress.org

*helps you find your elected officials using just your zip code.

Thomas.loc.gov

*helps you tracks the status of federal bills, including cosponsors. It's the source used by Congress and staff. You can also find out information about how bills become laws at Thomas.

AdvocacyAssociates.com

*provides “free resources” on effective advocacy (look for the link near the top of the page).

VOR.net/legislative-voice

*offers resources for H.R. 2032 advocacy, including the position papers we shared with Congress in June. An Action Alert, which includes sample letters in support of H.R. 2032, can be found here: vor.net/legislative-voice/action-alerts.

VOR.net/cost-comparison-study

*provides information for advocates and legislators on cost comparison research (facility v. community based care costs). More than ever, elected officials are concerned about costs. The cost comparison study on VOR's website is a critical resource.

A Sibling's Perspective

By Saskia Davis

I'd like you to meet my sister, Kathy. Here she is with a housemate and Pickles, the dog, in their living room at Fircrest, enjoying a game of "hat." It used to be that hats and rides were her favorite things in the world, followed closely by treats. Recently, we have had the pleasure of adding dogs to that list.

Fircrest has been Kathy's home for 48 years. As one of Washington State's Residential Habilitation Centers (RHCs), Fircrest has separate licensing as an ICF/MR and a nursing facility. With cerebral palsy, a mental age of about 2.5 years, bipolar disease, epilepsy and osteopenia, Kathy is best served in Fircrest's nursing facility. Licensing of Washington's RHCs varies: ICF/MR, NF, or dual. They are incredible resources.

Considering the road that Kathy and I have traveled together to where she is now, at Fircrest, I am thankful every day for all of her compassionate care and the friendships she has developed at her home.

Growing up, I spent every spare moment taking care of Kathy. I would do it all over again for her, though I would change some things. First, caring for Kathy at home was very difficult for my family. Some subsidy for services would have helped. According to the doctors, Kathy was to be a "vegetable," but our mother stubbornly "doctor-shopped" until she found a resourceful doctor.

After surgery at age 13 months, Kathy came alive, and with therapy plus our 24/7 support, she blossomed, slowly mastering basic toddler skills, despite her severe cerebral palsy. The trade-off for me was that I didn't/couldn't have much of a social life or have time for after-school activities. For our parents the load was huge between caregiving and making ends meet in view of uninsured medical and therapy costs. Ultimately, the stresses took their toll. Our parents ended up apart; and then our father died.

Knowing a bit about the beginning of our journey, and then, the wonderful support that Kathy has now, perhaps you can see why I am dedicated to ensuring that Washington State RHCs remain an option for Kathy and her peers across the state. The facility closures plus the cuts now being implemented to all—services for disabled people in our state risk not only forcing Kathy from her home, but

also will hurt younger families who are still caring for their loved ones at home. I really fear that the cuts will bring upon those younger families the same challenges Kathy and I and our parents faced so many years ago.

And that's why I advocate. I am absolutely motivated by

what I know to be in my sister's best interest. In this way, my sibling "point of view" is not that different from other RHC family advocates. We're all motivated by our love for our family member and are secure in the fact we know what's



Kathy, a housemate, and Pickles play "hat."

necessary for their happiness and protection. Most of us can remember the time when we had to face that we no longer could meet their needs at home. Most of us also tried "community" until that didn't work anymore, and we

know the initial heartbreak and ultimate salvation that "institutions" (RHCs) represent.

We all also collectively rejoice in the improvements we've seen, thanks to Medi-

caid, over the years. Federal funding and annual inspections ensure continual high quality, humane care. All of the people at Fircrest have a life where their conditions are managed in such a way that they can participate in daily activities: personal empowerment program, jobs, school and recreation, on and off campus.

While Kathy must be my priority, I also want to help as many as possible to have the resources they need; and I believe through sharing, we can find the answers we need. To those ends, I host the Developmental Disabilities Exchange at <http://ddexchange.blogspot.com/>.

Please visit. I'd love to exchange ideas with you.

Growing up, I spent every spare moment taking care of Kathy.

I would do it all over again for her, though I would change some things.

Ultimately, the stresses took their toll.

Our parents ended up apart; and then our father died.

VOR

"The best conference yet!"

Exceeding Expectations, Raising Our Voices & Honoring Our Own

VOR's 2011 Annual Conference and Washington Initiative in review

As promised, the 2011 Annual Conference offered up inspiring speakers and empowering grassroots advocacy training, resulting in the "best conference yet," as one long-time participant remarked. The conference evaluations received after the event also revealed satisfied participants. 86% of responding participants gave our speakers the highest rankings possible ("excellent" or "good"); 45% gave all four presenters a rating of "excellent."

Clare Ansberry Reporter, *Wall Street Journal*

Clare shared insight into the newspaper industry, noting that each reporter has her own style and perspectives, but that "there is less appetite for 'evergreens' – narratives that tell a story – much to my dismay." This fast



Clare Ansberry

pace, however, is an advocate's opportunity. She encouraged families to be proactive and give the reporters who cover disability issues a list of contacts to call upon when writing a story.

Clare tied her presentation together by reviewing several of her articles which feature the inequities in our system relating to access to services, aging caregivers, wages, and community oversight. Responses to each story result in ideas for the next. Participants appreciated Clare's insight and empathy. She offers thorough and fair reporting of issues facing people with disabilities and their families.

Sam Bagenstos Principal Deputy Assistant Attorney General, Department of Justice (DOJ) Civil Rights Division

Sam began his presentation by asking participants to not lose sight of areas of agree-

ment, such as the need to ensure quality services (no matter the setting), even as states are making significant cuts. Sam provided ample time for questions, which participants appreciated. Several participants challenged DOJ's interpretation of *Olmstead* and called on DOJ to seek and respect family input with regard to service options, including ICFs/MR. Participants appreciated the unique opportunity to share their perspectives directly with DOJ.

William Choslovsky, Esq. "The Illinois Example: How David beat Goliath"

Bill is among the team of pro bono attorneys who secured residential choice (community and ICF/MR) in Illinois, giving his sister and all of us hope for the future. This win for choice did not come easy. The challenge began in 2005 with the filing of *Ligas v.*



William Choslovsky

Maram, a class action lawsuit by Equip for Equality, Illinois' P&A. It was not until July 2009 when 2,500 "objectors" wrote the judge in opposition to a settlement agree-



Samuel Bagenstos

ment, and more than 200 people in court, that the judge finally up the settlement, as agreed to by the State, was not supported by those who would impact. As a result, the settlement was denied, those objecting were granted a new presentation, and the class was decertified. The presentation took us through this journey and concluded with several away lessons," including "don't let the power of an organized, united group working together, we don't need to pay Paul" and we can "grow our own slices." *See related article*

Grassroots Advocacy Workshop "Listen up Legislators!" How to Move Your Representation From Information to Action

This year's conference featured grassroots advocacy training led by Stephanie Vance



Stephanie Vance

top 10 things elected officials are asked to hear, the number one tool in the advocates' arsenal, keys to influence and secrets for inspiring an elected official to actually take action. Visit <http://www.youtube.com/watch?v=W2VJ4> to see Stephanie in action

Photo credit: Except where noted, thanks to Ed Orzechowski of "Advocacy Network," for the

Thank You Annual Conference & Initiative Sponsors!

The following generous sponsors made our event possible.

Gold Sponsors:

PHA – Sonoma Developmental Center; Walter E. Fernald Corporation; AFSCME.

Silver Sponsors:

American Health Care Association; EP Magazine.

Equipment Sponsors:

Cyberonics; Jane and Bob Anthony.

Bronze Sponsor:

The Sims Family.

Advocacy Workshop Sponsors:

Parents & Friends of Ludeman Center; Maryland Association of Nonpublic Special Education Facilities; Family & Friends Association of North Lake Supports and Services; Mary McCernan; Larry Innis.

Congressional Folders:

CCMR Advocates for all People with MR/DD in Mass.

Lunch Sponsors:

UPS; David and Mary Alice Swain; Robert and Evelyn Greene; Wrentham Association; Janice Moskowitz; Mark Engberg (in memory of Mary Beth Engberg).

Break Sponsors:

Fairview Families and Friends; NVTC Parents and Associates; Advocacy Network, Inc.

Session Sponsors:

Brooksby Village; Jane and Bob Anthony; Print Turnaround; Donald Stover; George Mavridis; UBS Financial Services; UPS; FORConn.

Recognition Participants:

Lutheran Home Association; and many organizations sponsoring participants.

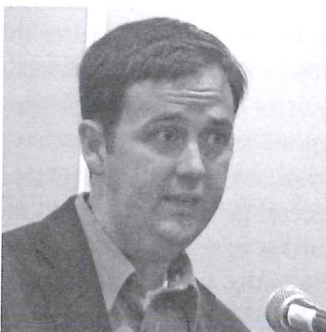
Thank you Sponsors!

Visit www.vor.net/events
for more details.

Underwoods receive third annual Jordy Engels Award

At VOR's national event, Kevin and Rebecca Underwood received the third annual Jordy Engels Award, presented by Carly Engels Johnston, sister to the late-Jordy Engels, for whom the award is named.

The Underwoods, from Wisconsin, were recognized for their outstanding advocacy on behalf of those who have no voice, making a difference every day with their dedication to VOR's mission.



Tate Heuer

Tate Heuer, senior legislative aide to Senator Mark Pryor (D-AR), speaks to VOR members during the 2011 Legislative Briefing, June 12, 2011 in Washington, D.C.

Knighton honored with 2011 Voice Award

The Voice Award is presented to individuals who have demonstrated unmatched commitment to the civil rights of individuals with intellectual disabilities. Ms. Knighton, VOR's second vice president and Georgia State Coordinator, was the 2011 recipient of this annual award. She was recognized for advocacy efforts on behalf of her daughter, Erica; her state-level leadership in Georgia; and her dedicated service to VOR as an officer, board member and state coordinator.

"Ann's dedication to the people we represent is remarkable," Robin Sims said. "She's leading the effort in Georgia, working hard to educate families, legislators, the media and lawyers, about the injustice of the Georgia Settlement, and she's not giving up. In her own words, 'we have much work to do and many miles yet to go.'"



Robin Sims (seated) presents The Voice Award to Ann Knighton

VOR

Arkansas: DOJ case dismissed; victory for choice

On June 8, Chief U.S. District Judge J. Leon Holmes held that the U.S. Department of Justice (DOJ) failed to prove that Conway, a state ICF/MR, should be shut down. According to the judge, the DOJ allegations were not "supported by the weight of the evidence presented at trial."

The Justice Department has been targeting state-run centers for the developmentally disabled in an effort to move residents into alternative settings. In Arkansas, Gov. Mike Beebe and Arkansas Attorney General Dustin McDaniel, whose office defended the state, both believe that the center should remain open.

"Judge Holmes' decision is a victory for the residents, families and staff of the Conway Human Development Center," Beebe said. "We have maintained throughout this case that these residents need a variety of op-

tions for care. But it is their families and guardians, not the federal government, who are in the best position to make those decisions."

"Other states have settled with the Department of Justice rather than go to trial on similar issues, but we were confident that the state could win at trial on the merits of the case," McDaniel said, noting that the lawsuit was filed over objections of guardians of center residents.

Holmes' decision cites the Olmstead ruling, saying Arkansas also has to offer center residents "the most integrated, least restrictive setting appropriate." But the judge said the federal government didn't meet its burden of showing the level of care at the center was not appropriate. VOR's Robin Sims was an expert in this case in support of Conway and families. (Source: *AP*, June 8, 2011)

From the decision:

"Most lawsuits are brought by persons who believe their rights have been violated. Not this one . . .

"All or nearly all of those residents have parents or guardians who have the power to assert the legal rights of their children or wards. Those parents and guardians, so far as the record shows, oppose the claims of [DOJ]. Thus, [DOJ] is in the odd position of asserting that certain persons' rights have been and are being violated while those persons – through their parents and guardians disagree."

Read the full decision:
<http://vor.net/get-help/legal-resources>.

Massachusetts: Judge nixes transfer of Fernald resident

A state administrative judge decided against the proposed transfer of Daniel O., a Fernald Developmental Center resident. The magistrate, Kenneth J. Forton, said in his ruling that Daniel's transfer from the Trapelo Road center would not improve his quality of life or the services he receives. The state is trying to transfer the last 14 residents at Fernald in order to close the center for good. Guardians of the final 14 have appealed the transfers.

Attorney Stephen Sheehy said he has appealed five decisions in favor of State's plan to move the residents. The Daniel O. decision is the first in the favor of keeping a resident at Fernald. (Source: June 17, 2011, *Waltham News Tribune*)

Supreme Court upholds right of VA P&A to sue for records

The U.S. Supreme Court affirmed the authority of the Virginia Office for Protection and Advocacy (VOPA) to pursue necessary legal remedies in fulfilling its advocacy for people with disabilities. VOPA had sued in federal court to obtain records of alleged negligent deaths and injury at a state psychiatric facility and at an ICF/MR. An appeals court blocked VOPA's attempt citing "special sovereignty interests" that bar one state agency from suing another because VOPA is one a few P&As that are housed in state government; most are not-for-profit organizations. VOPA appealed and the Supreme Court reversed, finding that when the Virginia state legislature established VOPA as an independent agency, it vested it with all authority necessary to carry out federal statutes to investigate abuse and neglect and to be able to use all available legal remedies. As a result the

Supreme Court held that the state agency could exercise the legal remedy of suing another state agency in federal court.

Illinois: Judge okays plan to support choice and expand community living

In June, a legal settlement approved in federal court (*Ligas v. Maram*) will allow individuals with DD to move to the community if they want, while also protecting the rights of individuals who prefer to live in larger facilities (*The Voice*, Spring 2011, "Blueprint for how to win").

An earlier settlement did not factor in choice, and as result was rejected by the court. The agreement brings an end to a lawsuit first filed in 2005.

**For your legal advocacy
"briefcase":**

The Supreme Court agrees that appropriate residential placement options for people with intellectual and developmental disabilities are best achieved when families, who are the most familiar with the needs of the residents, are involved (*Heller v. Doe*, 509 U.S. 312, 328-30 (1993)).

Also on the Web:
VOR Olmstead Resources
<http://www.vor.net/olmstead-resources>.

From one of our readers:

"The Legal News section in your VOR Update was just what I needed to continue reminding people it is about choice and need for the individual and that the family's voice must always be heard, respected and acted upon. It renewed my spirit of hope and made my heart sing. Thank you for all VOR does for people that do not have the ability to speak for themselves!"

Sarah Ross, Illinois

2011 State Report Forum

Sharing "lessons learned" is what VOR is all about. To help facilitate this process at the Annual Conference, VOR hosts an annual "State Report Forum." To read state reports from this event, visit: <http://www.vor.net/events>.

**New York: Progress claimed
In reporting abuse at group homes**

Roughly 40 percent of the allegations of physical abuse of the developmentally disabled at group homes and institutions in New York in recent months were not reported to law enforcement authorities. Yet, 40% represents a 17% increase. These facts were revealed as part of a series of legislative hearings prompted by a series in *The New York Times* detailing lapses in the state's care of the developmentally disabled. (Source: *New York Times*, June 13, 2011).

VOR's NY State Coordinators, Hugo and Cristy Dwyer, gave a VOR statement at one hearing on June 10. Calling for reform, VOR's statement pointed to a broken system of care

"from privately-operated 'Adult Homes,' which a federal court found to be violating the rights of 4,000 people with mental illness, to the state-operated group homes and developmental centers," and questioned the absence of DOJ and CMS federal oversight. The Dwyers, with VOR's support, have provided additional input to lawmakers on "best practices" for quality assurances in small settings.

**Illinois: More abuse, neglect
reported in group homes**

Across Illinois last year, more than 130 cases of abuse and neglect were investigated and confirmed in group homes for adults, a 33 percent increase compared to 2006. The reports of mistreatment and outright cruelty at the hands of low-wage workers with scant supervision, illustrate a mostly overlooked problem in Illinois. The state has 9,360 adults with developmental disabilities and another 359 adults with mental illness living in group homes, family homes and apartments run by more than 230 community agencies, costing the state \$340 million last year. (Source: *AP*, May 20, 2011).

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Speak Out for VOR Awareness in October!
www.vor.net/get-involved

Please remember that October is VOR Awareness Month!

With VOR's 2011 Awareness campaign we are asking all VOR members to educate existing members and recruit as many new members as possible. Plan on talking about the many things VOR is doing and the importance of being a member of the only national advocacy organization that opposes efforts to eliminate the facility option while also supporting the expansion of quality community programs. We need the help of all of you to get the word out and make October 2011 a really special time

for VOR Awareness, even if your family meeting is in September or November you can use those months as an opportunity to promote VOR Awareness. Family organization meetings are an especially great opportunity to get the word out about VOR with handouts and even speakers. If you would like a VOR representative to attend a parent/family meeting and visit your facility please let Julie know!

Julie can be reached at jhuso@vor.net or 605-370-4652. Thank you! Your VOICE makes a difference!



Your voice matters

By Julie Huso,
Executive Director

Words are never taken for granted at VOR.

As I struggle to find the words to write this message, I am reminded of Robin Sims. Not only did she accomplish so much for VOR, she inspired me in so many ways both professionally and personally.

Her words and her singing comforted and entertained so many, and her advocacy voice spoke so effectively for her children and all their peers with intellectual disabilities. Her voice for VOR and its members will always be remembered.

The many voices at the 2011 Annual meeting in Washington, DC were outstanding, from participants to presenters. The dedication and effort put forth by all attendees as they visited their federal legislators and worked diligently to ask for support

for H.R. 2032 was inspiring. Thanks to all participants for your continued efforts and support.

Every VOR member's voice is a vital partner in the mission and vision of VOR.

You express your support in advocacy and through dues and financial contributions. VOR is 100% privately funded and receives more

VOR is 100% privately funded and receives more than 95% of its financial support from families of individuals with intellectual disabilities.

than 95% of its financial support from families of individuals with intellectual disabilities.

Your continued membership dues



Julie M. Huso

and generous gifts enable VOR to continue assisting the many requests we receive daily from around the United States. We currently are active in 24 states by assisting with advocacy tools and support, letters and legal support. Because of each of you we are able to continue to assist you, your loved ones and families with intellectual disabilities.

Your voice and involvement are important to VOR. Thank you!

Crowd at the '11 Annual Conference applauds a presenter.



Michael Johnson and Julie Huso answer questions.

**More images from
"The Best Conference Yet."**



Questioners await opportunity to address concerns to DOJ rep. Sam Bagenstos.

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Sandra Reeves
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VOR's "Every Member Campaign"!

Together We are VOR.

You can renew your annual support by making a donation to the Every Member Campaign

To meet current and expansion needs, we have established the **"Every Member Campaign"** with a goal of \$48,000. This will provide the needed funding to meet the above goals while continuing our current advocacy programs for every member. VOR is over 3,200 members/households strong. It will only take \$20 per month or a \$240 donation for the year to meet this goal.

Please participate!

Our success and effectiveness is undeniable. The need for VOR is critical. VOR is a good and necessary investment. ***If not VOR, who?*** VOR is only as strong as our members' support.

Thank You! To participate, please use the contribution form below.

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.

VOR EVERY MEMBER CAMPAIGN

I would like to support the efforts of VOR with a:

- ☐ Pledge of \$20/month for 12 months for a total of \$240, and **pay by check to VOR** -

___ Please send me monthly email reminders.

OR

___ My \$240 for the year is enclosed.

- ☐ Pledge of \$20/month for 12 months for a total of \$240 and **pay by credit card** -

___ Monthly (\$20 will be automatically charged . each month for 12 months)

OR

___ Please charge \$240 once.

- ☐ Visa ☐ MasterCard ☐ Discover

Card Number: _____

Expires: _____ CVC (3 digit security) Code _____

Amount to charge: \$ _____

Signature: _____

Name _____

Address _____

City _____

State _____

Zip _____

Telephone _____

Email Address _____

- ☐ **My contact information has changed**

Membership Categories:

Individual --- \$40

Parents' Association --- \$200

Professional Assoc./Corp. --- \$250

An additional gift/pledge is enclosed for:

___ \$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. Jul11NL



836 S. Arlington Heights Rd., #351
Elk Grove Village, IL 60007
877-399-4867 toll free
605-271-0445 fax
www.vor.net

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

Non-Profit Org.
U.S. Postage
PAID
Permit No. 2857
Palatine, IL 60095

Tributes

IN MEMORY OF

Frank Boxall
Craig Brace
Mark Crawford
Arch Jones
Michael O'Riordan
Marian Snow
Robin Sims
Townes Stickmon
Cornelia Taylor
Johnny Ward

IN HONOR OF

Benjamin Bieker
Marlo Engels
Susan Fallis
Andy and Elsie Fowler
Robert Hazard
Tamie Hopp
Carly and Matt Johnston
Dana Lynn
Darlene Pickney
Michael Scully
Ethan Zuccarini

More tributes to the life, work & memory of Robin Sims

*The magnitude and impact of her
tenacious and effective advocacy
will live on. . . there is good reason
to be thankful for her legacy. She
was special.*

Bert and Leni S., Pennsylvania

*What a terrible, terrible loss of a
gallant lady who contributed heart,
soul and then some.*

Barry M., Idaho

*To Robin, just in case you can
tune in, somehow, I say a direct
thanks for all you have given. We
will continue your work for the
many who still need our defense and
advocacy.*

Saskia D., Washington

Making a will bequest to VOR

Will bequests are the most popular
and personal way to make a differ-
ence beyond your lifetime. A be-
quest 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 enti-
tled to an estate tax charitable de-
duction for the full, fair market
value of the bequest.

You would be supporting a chari-
table organization that you believe
in and passing on a legacy.

If you would like additional in-
formation on how to leave a be-
quest to VOR please contact Julie
Huso, Executive Director, 605-370-
4652 or jhuso@vor.net.