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August 24, 2012

VOR Weekly News Update

News and views for VOR advocates

VOR is a national organization that advocates for high quality care and human rights for people with intellectual and developmental disabilities

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VOR and You

1. VOR AWARENESS EVENT – FALL 2012!! Let's work to together to EDUCATE and RECRUIT

During the last 29 years VOR has accomplished many things due to the support of our loyal members and donors.

We are proud and excited about what we have been able to accomplish over the past two decades.

A woman I was talking to recently said,
“***I would not have known even where to start to get help for my son if it was not for VOR.”***

We now need your help to let others know about VOR’s important work.

With VOR’s 2012 Awareness campaign we are calling on ALL VOR members to EDUCATE existing donors and RECRUIT as many new members as possible.

We need the help of all of you to get the word out and make Fall 2012 a really special time for VOR Awareness. Is your organization meeting in Fall 2012? These family and other association meetings are a great time to promote VOR Awareness!

<u>How you can help</u>

We are calling on each of you to work with your facilities, family associations and others to increase the awareness and visibility of VOR!! There are lots of ways to help:

* Include an announcement or story about the Fall 2012 VOR Awareness Event in your newsletter and other publications.
* Host an event that encourages membership and involvement in VOR. This can be in your home, at your church, in conjunction with a family association meeting, or other venue.
* Send a letter or an email blast to your family association members and others about VOR, encouraging them to join and donate to VOR.

Here is a list of possible events you could host:

- Walkathon, bake sale, Tupperware party, Scentsy, Pampered Chef or other type of in home party and donate the proceeds to VOR.
- Have a raffle or silent auction, golf tournament, bingo, rummage sale or casino night.

* For other ideas visit www.fundrasisingweb.org

These are just a few ideas. You may have some great ideas too.

As you prepare for events or activities please let VOR know what you are doing and also how it turned out so we can share your success stories. We would like very much to include your story and pictures of activities in our newsletter and on our website. Please visit the VOR website at http://www.vor.net/get-involved/vor-initiatives for additional information.

The time is now!

Like many other organizations, this is a difficult time for VOR. Regardless, our Mission is too critical; we will not falter. With your help, VOR will continue to be successful as the only national organization that expressly opposes efforts to eliminate the facility option while also seeking expanded, QUALITY community options, recognizing that the individual and their family are the primary decision-makers.

“***When we were threatened by DOJ investigation, VOR was there for us with resources and support, I don’t know what our parents’ groups or myself would have done without this continuing always available support.” (Virginia VOR Member)***

Thank you in advance for your participation! We are here to help. Contact Julie Huso at jhuso@vor.net for information on handouts for your events, story ideas for your newsletters, or whatever you may need to make your event on VOR’s behalf successful.

Thank you again.

Now, go EDUCATE and RECRUIT for VOR Awareness in 2012!

2. Member Testimonial – Spreading VOR Awareness: “I’m so happy to see the work that your organization is doing.”

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Earlier this month, I received the following e-mail from a new VOR Member, Laurie Stengler. Her brother-in-law, Wayne, calls Murray Developmental Center home. She volunteers her time as the webmaster for the Murray Parents Association. Her letter is one of thanks for VOR - she appreciates VOR’s information and advocacy in support of choice – and also one of awareness. She has and will continue to pass along VOR’s information to Murray families and others through her association’s website.

This is just one example of how VOR members can assist with VOR Awareness and how our efforts are enhanced by working together. Feedback from members is encouraged and welcomed.

Laurie’s letter follows. Thank you, Laurie!

Sincerely,

Julie Huso

Executive Director

August 2012

Ms. Huso:

I am a family member and guardian of a Murray Center, Centralia, Illinois resident.

I discovered your organization through my association with the Murray Parents Association. I am so happy to see the work that your organization is doing. I intend to join your membership rolls this week. It has felt very lonely hearing from people up to the federal level that community placement is the best option for my brother-in-law. Wayne is totally dependent on others for every need, is unable to express his needs, has numerous medical problems and receives wonderful care at Murray. I am very concerned about the potential for abuse or neglect if he is placed in a small group home.

I recently created a website for the association to help educate others about the issues facing our loved ones and to serve as a resource to our members and hopefully others. I very much appreciate the kind words in the VOR weekly news update of 7/27/2012 and the link to our website. We have included a link to your website as well.

As I become more familiar with your organization and the information published on your website, I have found very useful information coming out regularly that I would like to publish on the Murray Parents Association website.

It is my hope that we can share information and that our website will soon be a resource for you as well.

Thank you,

Laurie Stengler

3. Angels of a Feather: A touching story featuring Jamie LaFleur, daughter to Terry (VOR Board Member) and Glenda LaFleur

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Nancy K. Duplechain * *Bonnes Nouvelles Evangeline* Newspaper * July 2012

He calls her his “little angel.” He says it with such tenderness you can’t help but smile. Terry LaFleur gently guides his daughter Jamie over to the small crate containing the two ring-neck doves. He lays out a little food for them to coax them out. When they finally realize it’s safe, the doves step out onto the table for a quick bite. Jamie delights in seeing the birds. Terry and his wife, Glenda, beam with pride at their daughter, as I am sure they have every time for the past six or so years.

Jamie [who calls Pincrest center home] smiles down at the doves which finish their meal and then, without warning, fly up into the trees where they will make their new home. We watch them for a minute, and they look down at us and then at their new surroundings—the Ville Platte Heritage Garden. They already look right at home. When they get hungry again, they can fly over to the bird feeder Terry made that hangs from one of the trees nearby. Each time they release a new pair of doves, they refill the bird feeder.

Terry and Glenda don’t do this for the birds so much. They do it for Jamie, thirty-three, who is mentally handicapped. “She always loved birds,” says Glenda. She says Jamie had a parakeet when she was little, but she, Glenda, was allergic to it. Years later, a friend gave them some ring-necked doves that quickly began to breed. In the beginning, they would let the offspring fly in their backyard, but the dogs would try to catch them. They decided to release them at the Heritage Garden. The original ring-necked doves live in a cage at the LaFleur residence. Glenda says that sometimes the offspring return to their home, so they leave some seed on top of the cage for them.

Glenda goes on to say how intelligent and spoiled the doves are. “Anytime someone goes out there, they rattle the cage because they want their treat!” The special treat is bread, which the doves adore. Looking at them now, it is easy to apply human characteristics to them; like happiness. Maybe that’s just my imagination. But if animals do feel emotions—and I believe they do—then I think what they feel the most is a sense of gratitude.

Seeing Terry and Glenda and how they are with Jamie, I also feel a sense of gratitude for people like the LaFleurs. I cannot remember the last time I met people so kind, selfless and genuinely good. Jamie is a beautiful spirit—an “angel,” as Terry calls her—who still has that sense of wonder that we all, at some time or another, wish we still had. She may not have wings, but Jamie, like her mother and father, are all angels of the same feather.

STATE NEWS

4. ILLINOIS: Community-Only Lobbyist says Illinois proposed closures moving at “a snail’s pace.” USE YOUR VOICE. COMMENT IN SUPPORT OF CHOICE

***Capitol Fax* (Illinois) * August 23, 2012**

Well-known community-only, deinstitutionalization proponent, Don Moss, said this about the pace of residents leaving Illinois Developmental Centers: *"Despite all the handwringing about the loss of state jobs, the process of downsizing our developmental centers is moving at a snail's pace."* Read More

If the notion of treating people like inventory being moved off shelves bothers you, COMMENT. There are extensive comments in response to this article already from both sides of this issue. Families of Murray and Jacksonville residents – who are most immediately impacted by closure plans – have weighed in. Lend your voice in support of choice too. Thank you.

5. MONTANA: Committee deadlocks on proposal to close Montana Developmental Center

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***Independent Record* (Helena, MT) * August 21, 2012**

A legislative panel Monday deadlocked on whether to introduce a bill in 2013 to eventually close the state institution in Boulder for the developmentally disabled, essentially killing the measure for now.

The 4-4 vote by the Children, Families, Health and Human Services Interim Committee came after lengthy testimony against the proposal, including opposition by Gov. Brian Schweitzer's administration.

Opponents of closing the Montana Developmental Center, which houses about 50 people and has a $15 million annual budget, said the center is undergoing vast improvements. They also said it's still needed as a place for treatment and care of difficult-to-treat clients who often are both developmentally disabled and mentally ill.

"If things weren't changing (at Boulder), I wouldn't be standing here saying 'no' to this bill," said Bob Runkel, acting director for the state Developmental Services Division, which oversees MDC. "But they are changing. The department has been very aggressive in implementing those changes."

Sen. Mary Caferro, D-Helena, led the charge to have the committee endorse the bill, saying the center has a history of negative reports on client safety and treatment.

The bill would have directed the state to start planning for closure of MDC by mid-2015, transferring its residents to community programs.

Its residents can be served just as well in community-based programs, she said, and at a much lower cost.

While the committee declined to advance the bill, Caferro or any other legislator could still choose to introduce it during the 2013 Legislature. In fact, Sen. Art Wittich, R-Bozeman, who voted for the measure, encouraged Caferro to do so.

The 4-4 vote from the bipartisan panel crossed party lines, with two Democrats and two Republicans each voting for and against the bill. Voting against it were Sen. Jason Priest, R-Red Lodge, Sen. Christine Kaufmann, D-Helena, Rep. Pat Noonan, D-Ramsay, and Rep. Don Roberts, R-Billings.

Noonan, who works for AWARE Inc., the largest private provider of community-based services for developmentally disabled people in Montana, voted in June to take a look at the bill, saying he wanted to “start the discussion” about whether MDC should be closed.

But on Monday, he said while he believed most MDC clients could be served in community programs, he felt advancing the bill could harm the clients at the Boulder facility.

Pursuing a bill that could close MDC could cause an “exodus of staff” from the center, and that could undo much of the good the Schweitzer administration has accomplished in trying to transform MDC in the past 18 months, he said.

The panel also was told Monday that the state cannot close the facility without paying off $6 million in loan costs incurred for past construction projects at MDC.

Read more and comment

6. CALIFORNIA: Parents of children and adults with special needs seek to set up support hotline

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Mercury News * August 20, 2012

[Note: The follow article details the efforts of families who have otherwise been abandoned by a system taking matters into their own hands and setting up a hotline to offer support to struggling caregivers. The hotline is prompted by a murder-suicide in Northern California, near where Agnews Developmental Center closed in 2009 and where Sonoma Developmental Center remains resource. Closures and closed admissions result, cruelly, leave families struggling in need without adequate services].

Parents of children and adults with special needs are seeking to set up a support line to help prevent tragedies such as the murder-suicide in March of an apparently overwhelmed Sunnyvale woman and her 22-year-old autistic son.

The goal is to have volunteers whom struggling parents can call when they feel alone and hassled. The volunteers will be parents of developmentally disabled people who have dealt with similar issues.

"I said to myself, 'I'm not going to let this happen to another mother,' " said Nicki Pecchenino, a Scotts Valley mother of a 15-year-old autistic son who is leading the hotline movement.

Before shooting her son and herself, Elizabeth Hodgins had told neighbors she was overwhelmed, tired and having difficulty finding a day program for her adult son. "The support system wasn't there," Pecchenino said.

San Jose resident Gilda Vincent offered to help soon after hearing about the hotline. As the single mother of 20-year-old Timmy, who has autism and Down syndrome, she said she knows how isolating it can be to care for someone with such disabilities. It can be tough just to take her son to the grocery store.

"It really takes over your life," she said. "Everything focuses on the individual with a disability and what they need. We're dealing with toddler and preschool-type behavior for 20 years or more. You don't realize how isolated you are until you get out among other people.

Nearly 80 parents have volunteered to help, she said. The goal is to support relatives of people with developmental disabilities such as autism, cerebral palsy, epilepsy and mental retardation in Santa Clara, Santa Cruz, Monterey and San Benito counties.

The Santa Clara County Mental Health Department has offered online suicide prevention training for up to 100 volunteers, Pecchenino said. She said the hotline will start after the volunteers complete the 45-minute course.

People wishing to volunteer or wanting more information can contact Pecchenino at nickipeck@sbcglobal.net.

"The emails have been so profoundly encouraging to me that we're on the right track," she said. "This is going to be my life's work."

Read More and Comment

Related:

VOR: Caregivers need options, not abandonment

Condemn a mother or a system

QUOTABLE

"*Your calls and e-mails do matter, probably more than you think. We have a system to track every call and e-mail and how many people are for or against something. Before they go to the floor to vote, members as for those numbers*" ~ A former senior congressional aide for two GOP House Members ("25 Secrets Your Congressperson Won't Tell You," *Reader's Digest* (September 2012)).

Tel: (605) 399-1624
Toll Free: (877) 399-4867
Fax: (605) 399-1631
Email: info@vor.net

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VOR
836 S. Arlington Heights Rd.
#351
Elk Grove Village, Illinois 60007
US