



Speaking out for people
with intellectual disabilities

www.vor.net



Feedback or questions?

info@vor.net

Join or Donate
to VOR Today!

Refer a Friend!

Advocacy
Toolkit for
Families

VOR.net:
Your one-stop
advocacy
resource

March 16, 2012

VOR Weekly News Update

News and views for VOR advocates

Featured Issue:

**March is National Developmental Disabilities
Awareness Month:**

Seeing is Believing – Showcase Your Center

Contents

1. Introduction to this issue: **Seeing is Believing**
2. **Virginia**: More Great Videos - Families Appeal To Lawmakers Not To Close Training Centers
3. **Ohio**: Cambridge Developmental Center: Our Community is Better Together
4. **Wisconsin**: Accomplished orchestra musicians make special connection with audiences
5. **Illinois**: In My View: Community care not best option for all
6. **Iowa**: Woodward Resource Center: A place for Jeff Paprocki to call home

Conclusion

*In March and throughout the year, showcase your center. Invite legislators. Invite your Governor. Invite the Media. Invite the Public. **Seeing is believing.***

Have you registered for VOR's Annual Conference and Initiative yet? Hurry! The deadline for early bird rates is approaching. [See VOR's website for complete details.](#)

1. Introduction to this issue: Seeing is Believing

This issue is dedicated to the good things that are happening in ICF/MR communities. From orchestras to swimming pools, from life-sustaining supports to the people who compassionately provide daily care (sometimes for decades), ICFs/MR are true communities. Celebrate these neighbors by inviting your local media and elected officials to take a tour: **Seeing is believing.**

You can also use the power of your pen to bring broader awareness and compassion for the supports provided at ICFs/MR for our citizens with profound intellectual and

developmental disabilities. Letters to the editor and longer opinion submissions can be powerful. Use your voices to sing your praise for your family members' homes.

2. Great Videos from Virginia: Families Appeal To Lawmakers Not To Close Training Centers

On Monday, March 12, Peggy Fox of WUSA-9 (Washington, DC) visited the Northern Virginia Training Center campus to meet residents, observe day program activities, and interview parents. [Click here](#) to watch this excellent coverage which showcases NVTC, its residents, families and services.

On Friday, March 9, [ABC 13 / WSET –TV featured Central Virginia Training Center](#) and the compassionate care received by twins with profound intellectual and developmental disabilities. Their mother, Martha Bryant, is fighting alongside other Virginia families as they challenge DOJ and the State's plan to close CVTC and other centers. "This plan is about cost savings, not about the best health plan for an individual," said Bryant. In his first ruling relating to the proposed DOJ and Virginia Settlement, Richmond District Judge John Gibney stated, "The General Assembly need not close the facilities. In fact, it can easily pass legislation to keep it open." It came as a surprise to Delegate Scott Garrett. He says the Commonwealth should reconsider. Bryant is optimistic about keeping her sons at their CVTC level of care. [Read the full article and watch the broadcast here.](#)

3. Cambridge Developmental Center: Our Community is Better Together

The Daily Jeffersonian (Ohio) * March 12, 2012

National Developmental Disabilities Awareness Month, celebrated annually through the month of March, will be publicized with this year's statewide theme, "Our Community is Better Together."

And according to Cathleen Ballinger, superintendent of the Cambridge Developmental Center, truer words were never spoken.

"It's all about our community," said Ballinger. "We have a well-qualified staff of more than 150 at the Center who teach people with disabilities, from ages 21 through 81, to live and work in the community just like everyone else. All of our people who live at the center have intellectual disabilities, about a third have physical disabilities as well. We teach them how to live an independent and normalized life, and be the best they can be. We are in our community daily, doing just that.

"There are five homes that constitute the Center where 70 people with disabilities live and work. We have comprehensive services of habilitation for teaching our people how to have a great quality of life. This involves activities of daily living, vocational training, medical services, occupational, physical and speech therapy, psychological services as well as psychiatric services.

"It is important to us that we convey that we are a part of the community this month and every month," said Ballinger.

"We patronize local businesses. We shop at the grocery stores, eat at local restaurants and bowl at King Pin Lanes. We also participate in local events, such as the Salt Fork Arts & Crafts Festival, the "Hoppy" Festival, and we will also be assisting at a new endeavor in the near future at The Salvation Army where we will serve food to those in need.

[Read more](#)

4. Accomplished orchestra musicians make special connection with audiences

Wisconsin State Journal * March 12, 2012

Music belongs to everyone — which is the reason violinists Suzanne Beia and Laura Burns, violist Christopher Dozoryst and cellist Karl Lavine are out and about on a chilly winter afternoon, heading to the Central Wisconsin Center [a state-operated ICFs/MR] with their instruments and a thick folder of music.

The musicians make up the string quartet HeartStrings, an

outreach program of the Madison Symphony Orchestra. Since 2006 the group has made the rounds of nursing homes, retirement centers, the children's hospital, family resource centers and facilities for people with developmental disabilities such as Central Wisconsin Center to perform a live, interactive program grounded in the principles of music therapy.

A recent afternoon visit to the Central Wisconsin Center drew audience members from across the center's campus, including staff from the business office, the lab and social work department, said Jan Holling, the center's director.

"It's just such a wonderful ending to your day," she said. Often, parents and guardians of the people whom the center serves drop by for the concerts, "and it's a really nice time for them to interact with their child."

[Read More.](#)

5. Illinois: In My View: Community care not best option for all

The State Journal-Register * March 10, 2012

About the author: Janet Anderson of Quincy is the mother of Ellie Voth, a resident at Jacksonville Development Center. Excerpts from her excellent editorial follow. To read her complete submission, [click here](#).

We conducted an extensive media tour of the Jacksonville Developmental Center on Feb. 27 to show what we've known all along. These state centers are small communities: campuses with appropriate housing, medical care, dining and recreational opportunities.

The tour highlighted what we welcome all in to see — that JDC is a safe, secure home for its 185 residents. Dr. David Iacono-Harris and his son Jonathon helped lead the tour. Jonathon calls JDC home not because it's convenient, cheap or just good enough. It's the very best option out there for him. The same can be said for my daughter, Ellie Voth.

Why would families like ours trust our precious loved ones, many with needs so great they must be watched and

cared for every minute of the day, with anything other than the best care possible? If community care was their best option, don't you think we would have them there in a heartbeat?

Your recent editorial refers to this closure process as unnerving for the residents and their families. What is really unnerving is how cavalierly our viewpoints are too often treated in this very important discussion. It's not simply that the community care experience was "bad" for our loved ones. This is not a case of being afraid of the unknown. These are fragile human beings, people who need stability and support above all else, and we know community care in Illinois all too well.

Some of our loved ones have tried community care only to regress greatly after making such good progress in center care. Others have posed a very real danger to themselves and others when the level of care they receive is not what it should be. JDC was available to take them back, avoiding even worse outcomes, including jail, serious injury or death. They need structure, loving and consistent care and the interaction with their friends and the community that they have at the centers. There is no substitute.

If we get this wrong, there is no turning back. There will be no safety net left in central Illinois, especially if the governor's plan to also close Murray Center in Centralia succeeds. That is why we will continue to be front and center at the Capitol this spring to make sure legislators don't buy into the "community care will work" myth. It's time our voices are heard and our choice for the best care for our loved ones is protected.

[Read more.](#)

6. Iowa: Woodward Resource Center: A place for Jeff Paprocki to call home

Des Moines Register * March 14, 2012

This is what freedom means to Jeff Paprocki, who now calls Woodward Resource Center, an ICF/MR home: When you're hungry, you can go to Pizza Hut, pick out what you want from the buffet and sit at a table like

anybody else.

Nobody will make you wear a helmet. Nobody will interrupt your meal to make you take more medication. If you want more pizza, a friend will help you walk back to the buffet to pick out another slice.

Paprocki, 23, reveled in such liberty on Tuesday, a few hours after he was released from a Des Moines hospital's psychiatric ward. He'd been locked in the hospital for more than five months, even though everyone agreed he didn't belong there. The hospital ward offered no therapy for his serious case of autism, but no other facility in Iowa's overburdened mental health system would take him. Finally, he reached the top of the waiting list for the Woodward Resource Center, a state facility (ICFs/MR) housing people with serious mental disabilities. An ambulance drove him 35 miles from the hospital to Woodward, which will be his home for at least a year. His mother, Martha, smiled as Jeff chomped down his lunch a few hours later. "He likes going out. He likes seeing people," she said. "He likes choices. Choices are a big deal. Freedom's a big deal."

Jeff suffers from a severe form of autism, a brain condition that can rob people of their ability to communicate with others. Some people with autism have fits of frustration, lashing out and hurting themselves, including banging their heads.

Jeff lived with his family until he was 15, when he became too much for his parents to handle. He lived in a Waterloo nursing home several years, then transferred to a group home in Nevada. Staff there sent him to the hospital last fall for what his parents thought would be a few days of medication adjustment. But the group home staff declined to take him back, saying they couldn't handle his outbursts. The only viable option appeared to be the state institution at Woodward, which had a waiting list for its approximately 185 beds.

Woodward's bed shortage is partly due to a steady decrease in capacity at such places under national efforts to move disabled people out of institutions and into smaller, community facilities. But critics say society hasn't put enough resources into strengthening the smaller

facilities so they can properly care for severe cases. So Jeff sat for more than five months in the psychiatric ward at Iowa Lutheran Hospital, whose leaders agreed with the family that they had little to offer him besides room and board.

Marsha Edgington-Bott, Woodward's superintendent, said Jeff's wait was unusually long. Part of the explanation, she said, was that despite its shortcomings, Iowa Lutheran gave him a safe place to stay. Some other prospective Woodward residents were in more precarious situations, she said, so they were bumped to the top of the waiting list.

The Paprockis believe Iowa Lutheran's staff members did the best they could for Jeff. But because their program isn't set up for autism, they offered him little therapy. They also didn't take him outside a single time in more than five months, his parents said, and they gave him more medication than an autism facility would use.

After the Des Moines Register wrote about Jeff's situation in February, his parents heard from several families with similar tales of frustration. His father, Jim, said Tuesday that he appreciated those calls, but wished he'd also heard from state legislators.

He knows they're working on a plan to reform the state's mental health system, but he hasn't seen them commit serious amounts of money for improvements. State leaders say the reforms will take time.

[Read more.](#)

Related Story: [The Boy Who Loved Tornadoes](#) is also a compelling true story of a teenager who found a home at Murdoch Developmental Center, a North Carolina ICF/MR, after being inappropriately placed in a psychiatric hospital.

Conclusion

*In March and throughout the year, showcase your center. Invite legislators. Invite your Governor. Invite the Media. Invite the Public. **Seeing is believing.***

Tel: (605) 399-1624
Toll Free: (877) 399-4867
Fax: (605) 399-1631

Email: info@vor.net

JOIN VOR. DONATE TO VOR. MAKE A DIFFERENCE

If you no longer wish to receive these emails, please reply to this message with "Unsubscribe" in the subject line or simply click on the following link: [Unsubscribe](#)

[Click here](#) to forward this email to a friend

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

[Read](#) the VerticalResponse marketing policy.

