

VOR Action Item Reminders

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VOR Weekly E-Mail Update
September 25, 2009

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H.R. 1255 Update

1. 65 and counting: Slowly but surely, H.R. 1255 gains support from Congress. Have you done your part?

STATE NEWS

2. MARYLAND: New Developmental Center replaces former center destroyed by fire; expands capacity

3. COLORADO: Budget cuts will force 32 disabled patients to move from their home, says state officials; families continue their fight, share their stories

VOR and YOU

4. YOUR MEMBERSHIP AND GIFTS MAKE A DIFFERENCE!!

VOR Membership and Contribution Form

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H.R. 1255 Update

1. 65 and counting: Slowly but surely, H.R. 1255 gains support from Congress. Have you done your part?

This last week, H.R. 1255 gained yet another cosponsor: Rep. Jerry Moran (R-KS), bringing the total number in support to 65.

Cosponsors don't just happen. They are the result of calls from one or many constituents.

Please make your call today. Tell your U.S. Representative to COSPONSOR H.R. 1255.

See, <http://vor.net/legislative-voice/legislation/hr1255>, for H.R. 1255 resources.
See, <http://www.vor.net/legislative-voice/legislation/hr-1255-cosponsors-vor>, for a list of cosponsors.

THANK YOU!!

2. MARYLAND: New Developmental Center replaces former center destroyed by fire;

expands capacity

September 19, 2009
The Daily Times

NEWARK - As the new Worcester County Developmental Center slowly rises out of the ground in Newark, center officials think it's time to give their neighbors an idea of what they can expect to see at the facility.

Newark and other area residents are invited to take a look at the plans for the \$7 million building at an informational meeting Sunday. Center staff will be at Barbely's restaurant with renderings of the campus and to answer questions.

WCDC Director June Walker said the meeting is an opportunity to let people "know what's coming."

"A lot of times, people are afraid of the unknown, so we are hoping to make it a known," Walker said. "We are hoping they get an idea of what we are bringing back."

Founded in 1971, the center provides educational, social, vocational and residential programs to developmentally disabled adults. Since 1973, the organization has been based out of a 77-year-old former school on Newark Road. A 2007 fire destroyed that facility, although Walker said at the time the structure "was already in a state of disrepair."

The new center will feature commercial-style kitchen and banquet facilities, a greenhouse, a laundry training area and more space to serve additional clients.

The organization has a waiting list with 73 people on it.

"The building is going to be bigger and more modern, and it's going to allow us to provide additional vocational services to the individuals we serve," Walker said.

The WCDC currently has about 90 people enrolled in its programs. The new building has space for almost double that number.

State and county grants and the insurance payout from the fire have paid for about \$4.5 million of the new building, which should be complete in 2010. The center is gearing up for a capital campaign to raise the other \$2.5 million.

Since the fire, WCDC has been using a facility on Market Street in Snow Hill, although Walker said the center is looking forward to getting back to Newark. Sunday's meeting, she said, is part of that process

3. COLORADO: Budget cuts will force 32 disabled patients to move from their home, says state officials; families continue their fight, share their stories

Summary: There is a great online slide show that accompanies this article: <http://www.9news.com/9slideshow/gallery.aspx?slideshowname=9-20-Med-Ctr&N=5>. The slide show features some of the residents, and their extreme needs, if the facility closes. These pictures truly do speak a thousand words.

September 20, 2009
9News.com

Denver - The state is moving forward with plans to close a skilled-nursing facility in Grand Junction next year, despite several families' efforts to keep it open.

Grand Junction Regional Center is a 32-bed facility that serves people with severe developmental disabilities. Governor Ritter announced in August the facility would close, saving tax payers \$1.3 million. It's part of a bigger plan to cut at total of \$320 million from the state budget over the next year.

Department of Human Services, Deputy Director of Veteran's and Disability Services, Tim Hall says closing the Grand Junction Regional Center wasn't a decision based solely on money.

"It's consistent with what other states are doing," he said.

Hall says since the late 1980's states have moved away from institutions like Grand Junction Regional Center and into community based facilities like nursing homes and group homes.

"We have been downsizing the institutions as they are called and putting people into the community to work with our other providers in a more integrated setting," Hall said.

The Robison family is among those who fear their sons and daughters won't have the same quality of life in other settings like they have had in Grand Junction. "You can just see, he loves those people and the thought they won't be there for him anymore is just heartbreaking, they're family too," said Carole Robison-Brass.

Robison-Brass's brother Ricky has lived at Grand Junction Regional Center since 1963. On Tuesday, his caregiver of 19 years, and his caseworker drove him to Denver to be with his family for his birthday. Ricky is turning 50 years old.

"It's amazing!" said Marty Robison, Ricky's dad. "I didn't think I would ever see him at 50 years old."

Ricky was born a happy, healthy baby in 1959, but at 5 months doctors made a mistake that would change his life forever.

"He got meningitis and it was misdiagnosed, they told them it might be strep or what ever was going around at the time and his fever spiked so high that there was so much damage done, there was nothing anyone could do," said Carole.

At the time doctors thought Ricky would be lucky to live to be 5 years old.

And by the time he turned four, the family received more bad news. Ricky's mother was terminally ill and the family was forced to make the toughest decision of their life, allowing someone else to care for their son.

"It's tough, when you have to turn around and walk away and leave your son, it's hard," said his father.

Their decision turned out to be the best for Ricky. For the past 46 years family member say their son and brother has thrived.

"He goes to petting zoos and movies, and he loves that," said Carole.

Ricky is non-verbal and immobile so he requires around the clock care. Grand Junction Regional Center provides an all inclusive environment where patients like Ricky have access regular doctors, nurses, and a dentist. The Robison's fear Ricky won't get the same level of care elsewhere.

"We do not want him moved. We want him to stay right where he is," said Mr. Robison.

Hall says he understands family's concerns, but he feel confident this move will result in even better outcomes for patients like Ricky.

"We're not compromising our services, we're not doing a step down here we're just transitioning people to a different environment that will also be very high quality," said Hall.

Doctors believe Ricky could live to celebrate another 10 years according to his family, and they want to make sure he has every opportunity to do that.

Department of Human Services wants to work with the families to find the best option for all 32 patients. Parents are invited to attend a Providers Fair on Monday to look at community based homes in the Grand Junction area.

Grand Junction Regional Center is scheduled to close in February, but Hall says his staff is prepared to take as long as necessary to find the best situation for every patient and their family.

Other families impacted by the closure wrote about their situations.

Peggy McFadden's daughter has lived at the Regional Center since 1952.

"My daughter, Dovie Lynn McFadden, became a patient at the Regional Center in 1952. She is as helpless now as on the Christmas Eve when she was born. She needs constant care 24-7. She has never spoken a word, only makes sounds...[never] sat up by herself; been able to hold anything. She is a 62-year-old infant. If it wasn't for the loving care from the Doctors, nurses, and care givers she wouldn't have lived this long. She is a person, not a thing.

lease do not close the center."

Connie and Dennis Brady's son has lived at the center since 2005.

"Tyler Brady has lived at home for 21 years. He was born with a severe form of spina bifida, a birth defect that sometimes creates serious complications similar to a spinal cord injury. He needs help with basic care from feeding to toileting to rolling over in bed. As his medical and physical needs increased over time he became more and more isolated at home. Tyler is frequently on bed rest for days or weeks at a time due to his condition. Over the years, we researched many options, from creating an apartment/caregiver arrangement in our home to looking at a local group home setting. Because of his complicated medical needs, the only facility that was workable was the Grand Junction Regional Center. Tyler has lived there now for four years. He is

no longer isolated, because the staff work very hard to provide and attune their care to meeting his needs. If bed rest is necessitated, they work hard to ensure that he is not isolated by giving him the social and activity distractions. We know and trust the care providers and have been thrilled to know they have come to love and care for him as much as we do."

Gini Springmeyer son has lived at the center since 1960.

"Kenny was born on the 4th of July, 1957 amid high hopes and excitement. He was joining two brothers 3-1/2 and 1-1/2 years older. His birth was a tough one, as the cord was around his neck. Little did we know the long lack of oxygen (over 10 minutes) would render such a devastating diagnosis. When he was 3 years old his family doctor felt a court order was necessary to admit him to the Grand Junction Home and Training School (now the Regional Center), as his oldest brother was afflicted with cerebral palsy and there was no supporting family to assist with the care required. The tears over this decision have been many, but Kenny has thrived beyond expectations. His home is in Spruce Dorm on the Regional Center's campus, where he has lived for 49 years. Even though Kenny is not ambulatory and does not talk, he is very expressive as he scoots around and laughs at everyday things. He loves his "family" at Spruce. His particular care keeps him far healthier than one would expect. At 95 pounds he is a lightweight, fighting for his home and his life. Kenny is loved."

VOR and YOU

4. YOUR MEMBERSHIP AND GIFTS MAKE A DIFFERENCE!!

VOR is the only national advocacy organization that expressly opposes efforts to eliminate the facility option while also supporting expansion of quality community programs. VOR advocates that final determination of what is appropriate depends on the unique abilities, needs and desires of each individual, with the input of family guardians where necessary and appropriate.

Editor: Tamie Hopp, VOR Director of Government Relations & Advocacy

THANK YOU FOR YOUR SUPPORT!

TO JOIN OR CONTRIBUTE: \$25 per individual, \$150 per family organization, or \$200 per provider/professional organization. Extra donations are welcome!

You may pay by check or credit card
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