Speaking out for people with intellectual & developmental disabilities

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/VOR

@VOR_NET

info@vor.net

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VOR Weekly News Update

News and views for VOR Advocates

It's not too late!

Registration and Sponsorship Details are available for VOR's Annual Conference and Washington Initiative, June 8 - 12, 2013 in Washington, D.C. Please join us! (limited hotel availability; first come, first serve!)

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jeopardy
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VOR and YOU

1. “VOR’s Quality in the Community Initiative” in EP Magazine

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EP Magazine *** May 2013**

If there is one thing that advocates for people with intellectual and developmental disabilities can agree on, it is that quality matters – in all settings, and in all places, serving people with intellectual and developmental disabilities (I/DD).

In June 2012, with this unifying vision in mind and a desire to address a growing need, the VOR Board of Directors adopted assuring quality in community settings as a strategic initiative for the organization.

“VOR represents many families of individuals who receive quality facility-based care,” said Ann Knighton, VOR President. “These families take comfort in the federal regulations and oversight that dictate a certain, consistent, level of care.”

Read more

EP Magazine subscription information

2. VOR: “A rare opportunity to do more with more: Allow more people to access the good care available at the Wyoming Life Resource Center”

***The Lander Journal* * Community Voices (p. A4)** *** May 8, 2013 * Connie Howard, VOR Wyoming State Coordinator and Tamie Hopp, VOR Director of Govt Relations & Advocacy**

Like other states, Wyoming faces difficult decisions on how best to care for its citizens with intellectual disabilities (formerly “mental retardation), developmental disabilities (such as

Reminders:
Help VOR Grow!

$5,000 Challenge: Help VOR send advocates to Washington, D.C!

Make a Lasting Impact with a Will Bequest

VOR.net: Your one-stop advocacy resource autism and cerebral palsy), and brain injuries.

In March, the Wyoming legislature directed state officials to consider the cost efficiencies of the Wyoming Life Resource Center (WLRC), which is home to about 90 people with profound intellectual disabilities and brain injuries.

Many more individuals with disabilities are served in their family homes or by community providers – small, privately operated residences. Some legislators and advocates support smaller settings feeling that these homes provide higher quality of care and more “inclusion” for less money than the WLRC.

Unfortunately, the best mix of care for our citizens with disabilities is not “black and white.” Smaller is not necessary better, more inclusive or cheaper. Likewise, not everyone is best supported at WLRC which caters to individuals who require total care and whose needs are very specialized.

Just like a hospital will triage the care it provides its patients – from outpatient care to the intensive care unit – so must Wyoming’s disability system. There will be people who require the highly specialized “intensive care unit” supports that only WLRC can provide and others who can and should receive high quality, individualized care in less specialized settings.

Individualization is the key and to ensure individualized supports there must be options; there must be choices.

For too long, WLRC efficiency has been compromised by forced downsizing and lack of admissions. Yet, there are citizens who are isolated in their own homes due to lack of reliable transportation, lack of staff, or for their safety. In one case, a 17-year-old boy with multiple disabilities, including autism, and dangerous outbursts will wander out of his home but has little sense of danger if not supervised. His mother installed alarms on all the doors to keep her son safe. Consider how exhausting and stressful their living situation is with war zone like alarms frequently going off and supervision required at all hours. Is that integration?

With regard to WLRC's efficiency, why not think outside the box and ask whether the Center would operate more efficiently with more residents and by increasing the number of non-residents that receive health care supports from the Center's professionals as outpatients.

With so many Wyomians with disabilities desperate for adequate care and supports, a natural and tempting response would be to take from WLRC residents and give to individuals going without. A "robbing Peter to pay Paul" approach, however, has not worked well in other states and will leave many Wyoming citizens without adequate care. Cutting services in the face of such need is antithetical to expanded services. As a result, current WLRC residents and "outpatients" will suffer when services are dismantled and lost, and those who could have benefited (now and in the future) will compete for a slice of a smaller pie.

It is possible to make the pie bigger and serve more people. Indeed, Wyomians have a rare opportunity to do more with more, if there is a willingness to think outside the box and buck national trends. The Wyoming Life Resource Center is a jewel. Why not open its doors and serve more very disabled and deserving citizens?

VOR is a national nonprofit organization advocating for high quality care and human rights for all individuals with intellectual and developmental disabilities. Connie Howard is VOR's volunteer Wyoming State Coordinator. Her son, Mark, has profound intellectual disabilities and has received high quality, specialized supports in both facility-based and community-based settings. Tamie Hopp resides in Rapid City, SD, and serves as VOR's Director of Government Relations and Advocacy. For more information, visit www.vor.net.

3. National Family Group Calls on Congress for Choice

***Outreach* (page 10)** *** California Association of Psychiatric Technicians * February/March 2013**

The only national group advocating for a full range of quality residential and service choices for people with developmental disabilities is calling on Congress to investigate violations of the Americans with Disabilities Act and other laws by federal agencies.

Representatives of VOR wrote letters to all new and returning members of the 113th United States Congress in order to highlight executive-level agencies' deliberate misrepresentations of the ADA and the Developmental Disabilities Act as well as abuse of their governmental power as they continue their campaigns to close developmental centers, which are home to thousands of Americans with developmental disabilities.

Read more

State News

4. Illinois: Murray Center gets more bad news; new delays in state payments

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***News-Democrat (SW Illinois)* * April 30, 2013**

Private providers and community agencies that will care for residents of the skated to-be-closed Warren G. Murray Developmental Center can expect new delays in their state payments of up to four months.

Supporters of the Murray Center say the delayed-payment plan is evidence that closing the institution in Centralia is a bad idea.

"At a time when the state is trying to force the severely and profoundly disabled out of Murray Center and into the community, the state admits it cannot pay its bills," said Karen Kelly of O'Fallon, whose adult son is a Murray resident.

The Illinois Department of Human Services sent a letter Monday to providers of services for the developmentally disabled, informing them that the state's poor financial condition is "resulting in significant funding delays."

The payment delay will be nearly two months for some types of facilities, such as day programs, child group homes and what the state refers to as Community Integrated Living Arrangements, or CILAs, which are group homes for eight or fewer adults with developmental disabilities.

The delay will be about four-and-a-half months for other types of facilities, such as Intermediate Care Facilities, which are residential facilities for adults who have developmental disabilities as well as behavioral or medical issues that require 24-hour treatment or care.

Most Murray Center residents would end up in CILAs or Intermediate Care Facilities.

Josh Evans, legislative director for the Illinois Association of Rehabilitation Facilities, a trade association for community agencies that provide services to people with disabilities, said the state already owes about $220 million to such providers under this year's budget. The state has a roughly $9 billion backlog of bills owed to various vendors.

Evans said some service providers have "maxed or extended lines of credit" in order to meet payroll and keep their doors open. Evans said the only reason there have not been closures of community-based providers is because the state comes to the financial rescue at the last minute.

"We're under a put-out-fires scenario. The provider will call the state comptroller and say, 'Hey, I need to make payroll next week, and don't have any cash on hand,'" Evans said.

Evans said he can "see why there would be reason for concern" for people whose relatives are being forced to leave state institutions and sent to centers that are paid late and scraping for cash.

Kelly said she and other parents have been asking state officials what will happen if a private facility suddenly closes its doors due to problems with state payments, and there are no state institution to go back to as a safety net.

The state last week began moving residents out of Murray Center, which is scheduled to close in late fall. The center has about 260 residents and about 530 employees.

Read more

5. Connecticut: Guardians demand training school input

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Republican-American (Waterbury, CT) *** May 1, 2013**

Guardians and family members of Southbury Training School residents want a new state task force to consider the future care of clients while it explores uses for the buildings and land on the sprawling campus.

Gov. Dannel P. Malloy last week appointed a nine member panel that will chart a long-term plan for the grounds and buildings, home to fewer than 400 severely mentally disabled men and women.

Members of the Home & School Association, the nonprofit organization of guardians and family members, say the task force must also examine the current and future care of clients, and consider reopening the training school to new admissions.

No new residents have been admitted since 1986, and the state has offered all clients the choice to move to community homes.

Guardians and family members say the

training school, in north central Southbury off Route 172, offers clients a better quality of care than can be found in group homes, and they suspect there is a movement in Hartford to close the institution, the last of its kind in Connecticut.

In a letter to Malloy, Martha Dwyer, president of the Home & School Association, suggested expanding the services offered by the training school, including opening a skilled nursing facility.

There is precedent for making the training school's services available to people who don't live there. Approximately 600 people with mental and developmental disabilities now receive dental care at the institution.

"We must do more than just study the future of the infrastructure at STS," Dwyer wrote. "We cannot consider what is to be done with the STS campus without considering the broader issue of what constitutes appropriate and cost-effective care for people with intellectual and developmental disabilities."

Dwyer also wants the task force to consider whether the state has enough capacity in its group homes and other community-based centers to care for training school residents.

She said state funding of the community-based system has increased by only 1 percent over the last five years, and that some providers are no longer operating.

She said membership on the task force should be expanded to include a guardian or family member of someone on the state's waiting list for care, and someone who lives in a nursing or group home.

Malloy has said a guardian or family member of a training school client will be appointed to serve with state officials, Southbury First Selectman Ed Edelson, a Southbury resident and business owner and someone with knowledge of the training school's nearly 75 year old infrastructure.

“We think it is critically important that this task force be viewed by the public as an independent, fair and impartial panel whose members have the necessary expertise to produce a study of lasting value,” Dwyer wrote.

6. New Jersey: Assembly approves bill reversing developmental center closures

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***The Record* * April 29, 2013**

The Assembly approved a bill today that would keep open North Jersey’s two developmental centers for disabled people, but the legislation’s future remains uncertain.

A state task force issued a binding decision in August to close the North Jersey Developmental Center in Totowa and the Woodbridge Developmental Center in Middlesex County, which have a combined 750 residents. It allowed the state’s five other centers to remain open.

Today’s legislation, which passed by vote of 44 to 29 with two abstentions, would split the state into four regions, each of which must have at least one developmental center. The regions are divided in such a way that the Totowa and Woodbridge developmental centers would both have to stay open.

But the bill has not been introduced in the Senate. Separate legislation now moving through that chamber rescinds the task force report and creates a new panel to evaluate developmental centers, focusing on the needs of the residents.

Family members and other opponents of the closures said the decision would leave North Jersey with no developmental centers and would move the disabled residents far from their homes.

“State developmental centers must be accessible in all regions,” Assemblywoman

Shavonda Sumter, D-Paterson, said in a statement. “The center provides a valuable service to our communities. One less center in the state could put the quality of this service at risk.”

But Republicans have argued that the task force’s decision should stand. Its report was binding so that it could close the centers without worrying about political pressures, the lawmakers say.

Read more

Read related opinion: **"*One size doesn’t fit all*,"** by Deborah Smith, mother and Board Member of Save Residents’ Homes at Developmental Centers (“For those with profound intellectual disability, the least restrictive environment for this population is developmental centers where comprehensive medical care is provided to the residents under the Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) federal-care model for the most vulnerable of our society. Most of these residents have limited or no speech. They are toddlers in adult bodies, and most have a variety of chronic medical conditions. Developmental centers provide healthcare and social services, as well as medical services based on the residents needs determined by a team of professionals in conjunction with input from parent or guardians and family members.”)

7. California: Challenges for patients as Pomona’s Lanterman Center closes

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***The Press-Enterprise* * May 3, 2013**

Lanterman Developmental Center in Pomona is more than two years into a closure process that has moved hundreds of former residents into community care facilities in the surrounding area and beyond.

Officials say they are going to great lengths to assess the needs of Lanterman patients, three-quarters of whom have profound intellectual disabilities, before they are moved into special adult residential facilities.

The process involves risk, however. Last September, a former Lanterman patient named Stephanie died after being moved from the developmental center to a residential care home in Colton.

Some advocates for families with relatives at Lanterman said they worry there will be more deaths as medically fragile residents, many of them elderly, move into homes overseen by a dozen nearby nonprofit regional centers that arrange services for the developmentally disabled. Workers at the community facilities may not be as experienced as Lanterman employees, they say.

Lanterman, opened in 1928 as the Pacific Colony, is the second-oldest of the state's four developmental centers. It was named after former Republican Assemblyman Frank Lanterman in 1979.

Other developmental centers are in Costa Mesa in Orange County, Porterville in Central California, and Eldridge, in Sonoma County. The state also operates Canyon Springs in Cathedral City. As of April 24, there were 1,521 people in the state facilities.

Most developmentally disabled people receive services arranged by 21 regional centers that contract with the state. Inland Regional Center, the state's largest, serves more than 25,000 people in Riverside and San Bernardino counties.

In 2010, the Inland center had 51 clients inside Lanterman. As of May 1, only five remained there.

"We've done a pretty good job finding community placement for them," said Carol Fitzgibbons, the executive director of Inland Regional Center. But as the numbers decline, "they get tougher and tougher (to place). They have so many needs. To try to replicate that in the community is really difficult."

State officials said they learned lessons from the closure of Agnews Developmental Center in San Jose, a process that began in 2003 and finished in 2009.

Officials set a closure date that, as it approached, triggered anxiety among family members. Several times, though, the state postponed the date, and the cycle repeated. There is no such timeline for Lanterman's closure, although officials tentatively expect the last patient to be gone in fall 2014.

Other challenges confront the state. It has been more difficult than expected to buy, remodel and license homes to house the transferred Lanterman patients.

The homes need four to five bedrooms, but can't have a swimming pool. And some planned home purchases have been opposed by the surrounding neighborhood. Also, few of the hundreds of state employees at Lanterman are going to work for community providers caring for the former Lanterman residents. State pay and benefits generally are better.

Read more

8. California: Porterville Developmental Center to lay off 54 employees

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***The Recorder* * May 2, 2013**

“They’re not cutting costs, they’re cutting professional services and staff for our residents, livelihoods for our employees and their families, and income for our struggling local businesses,” said Mike Simental, the California Association for Psychiatric Technicians’ Porterville Chapter President. “We’re dedicated to providing the best care for our residents, whatever the budget says, but we say more employees are needed – not less.”

Brady Oppenheim, CAPT consultant, believes the cuts will only result in an increase of overtime numbers. “It’s very ironic. We already have an issue with massive overtime and staff doing its best to keep the staffing ratio up and running,” Oppenheim said.

Read more

Read related CAPT press release

Read Related: PDC's greatest natural resource — volunteers and donors

9. Arizona's highest ranking in disability services in jeopardy

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Disability Policy Research News Alert * Disability Research Consortium (Mathematica) * May 10, 2013

The Arizona Republic reported on the annual United Cerebral Palsy state rankings of disability services for people with developmental disabilities. "Arizona [ranked] first overall for the fifth time in the survey's seven years, owing largely to the state's nearly universal use of home-based services for people with developmental disabilities and its managed-care model, which both help keep costs down. But advocates for people with disabilities predicted that the state's lofty ranking would tumble if lawmakers fail to restore cuts to the rates paid to service providers, causing group homes to shutter, waiting lists to increase and caregiver turnover and quality to suffer." The state rankings are based on a survey conducted by United Cerebral Palsy.

Quotable

"*The more I help others to succeed, the more I succeed.*" ~ Ray Kroc, Founder of McDonald's Corp.

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Calendar Reminders:

*** Recorded - Listen Here. Tuesday, April 23, 2013 - 12:00 pm central / 1:00 pm central**
FREE WEBINAR: How Congress Works: The Basics. Hosted by Peter Kinzler and Larry Innis.

*** TONIGHT!! Friday, April 26, 2013, 6:30 pm, *Mila in Concert:*** Benefit concert by renowned concert pianist, Mila Belakova. Click here for concert poster, press release, and details.

***Through May 1, 2013 (for recognition opportunities):** Be a Sponsor. Get a Sponsor: Support VOR's Conference and Initiative.

Sponsorship opportunities, in partnership with *EP Magazine*, are now available.

*May 6, 2013: HOTEL RESERVATION DEADLINE

*** Sunday, June 9, 2013**

VOR Annual Conference * Washington, D.C. Registration now available. Details online.

*** Begins Monday, June 10, 2013**

VOR Washington Initiative (Begins Monday, June 10, 2013) * Washington, D.C. Details online.

*** AHCA/NCAL to host Intellectual and Developmental Disabilities (ID/DD) Day – October 6, 2013**. Details online.

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