



Speaking out for people
with intellectual disabilities

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On the Website:

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A message from VOR's Executive Director

Dear VOR Friends,
I would like to thank all of you for your continued support of VOR.

Over the past year, members have shared many stories

regarding their loved ones and we have used those stories to help advance VOR's advocacy voice for those who can't speak for themselves.

As your national advocacy organization, VOR supports all individuals with intellectual disabilities, regardless of where they live, and their families as primary decision-makers. VOR is the only national advocacy organization that supports an array of service options to meet diverse needs across the disability spectrum. The happiness, well-being and very survival of the individuals depending on these services require nothing less.

Without you, VOR would not be a strong, national advocacy voice for choice. Thank you!

Please join us in Washington, D.C. We invite you to attend the Annual Conference and Washington Institute June 9-13, 2012 in Washington, DC to learn more about VOR's national advocacy and carry our shared message to Congress.

If you cannot attend please consider being a [Conference Sponsor](#). Details about our Conference, the Initiative and Sponsorship are available on [VOR's website](#).

Thank you,

Julie Huso

Executive Director

2. Second Request: CMS seeks best practices and research relating to aging and people with intellectual disabilities

CMS, in its ongoing efforts to improve the care provided to clients in ICFs/MR, is compiling research materials on the topic of aging for individuals with intellectual disabilities (ID). CMS is seeking any resources on this topic, including:

- Any recent studies, publications, resource books or literature addressing the aging process as it relates to individuals with ID;
- The names of any national organizations which advocate for the rights of the individual with ID who is aging;
- The names of any Universities currently conducting research on this subject; and
- Any assessment tools that are available specifically focused on the impact of aging on ID clients.

This is a second request distributed by CMS. If you have resources that could help, please respond as soon as

possible to Kelley Leonette at kelley.leonette@cms.hhs.gov.

3. Study: Many Adults With Disabilities Do Nothing All Day

A new study concludes that people with developmental disabilities who are inactive each day are also more likely to have severe disabilities, receive fewer resources, and have parents who were less able to provide care. In these cases, a large percentage of siblings also reported having poorer mental and physical health than other siblings as well as weak relationships with their brother or sister, calling into question their viability as long-term caregivers. Unfortunately, the study's findings did not consider the impact of residence on level of daily activity. The study included individuals in all settings with the majority (88.9%) living in family homes, group homes, and other small settings, and the remainder in licensed facilities (11.1%).

VOR feels that the detrimental impact on aging caregivers – parents or siblings – is predictable. People with severe developmental disabilities take more care, more time and energy and over time such caregiving takes its toll. Caregivers have less energy and motivation to search for more services, especially considering the many obstacles to finding services that are often in place. It is our experience that many local agencies do not tell families all that is available or families are discouraged from asking for services due to lack of funding and long waiting lists. Many years ago, author Fern Kupfer addressed this very real concern:

“No politician is going to say he is against caring for the handicapped, but he can talk in sanctimonious terms about efforts to preserve the family unit, about families remaining independent and self-sufficient. Translated, this means, ‘You got your troubles, I got mine.’” (Kupfer, F., (December 8, 1997). My Turn: Home Is Not For Everyone. Newsweek).

In response to the "Do Nothing" study, one VOR Board Member remarked, “I hope this study is not interpreted as a need to better educate parents to become better caretakers, rather than actually providing services.”

Read [related article here](#).

State News

4. New York: Ortiz - make Jonathan's Law permanent

Legislative Gazette * February 21, 2012

In remembrance of the five-year anniversary of the death of Jonathan Carey, Assemblyman Felix W. Ortiz, D-Brooklyn, last Wednesday hosted an event, alongside Jonathan's father, Michael, and other Albany lawmakers, announcing a bill that would extend Jonathan's Law permanently.

Jonathan's Law, enacted in May 2007, ensures parents and legal guardians who have developmentally disabled children living in government-run facilities, have access to medical records and child abuse investigation files. The law was named in honor of Carey, who, at age 13, died at the hands of a direct care worker employed by the O.D. Heck Developmental Center in Schenectady.

In a prior incident, the Office of Mental Retardation and Developmental Disabilities, denied access to Jonathan's parents to view records into an investigation over allegations their son was physically abused at the Anderson Center for Autism in Hyde Park.

Ortiz, who chairs the Assembly Mental Health Committee, said Jonathan's story has resonated throughout the state and country. The "culture" of the Office of People With Developmental Disabilities, the agency's new name, Ortiz said, must continue to change and there must be greater assurance that future hires will come bearing the necessary training, responsibility and accountability. "Individuals with developmental disabilities are the most vulnerable population in our community," said Ortiz. "It's our job to make sure they receive the best quality of care and I will continue to fight for these individuals and their rights."

[Read more.](#)

5. Illinois: Trickle down revenue loss effect seen from facility closures

State Journal-Register * Feb. 18, 2012

Jacksonville and Lincoln both are medium-size cities in central Illinois. Both have state prisons. Both have two colleges. Both used to be home to MII Inc. manufacturing facilities before they were shuttered.

And sometime this fall, they will each have lost a developmental center to state closure, unless those opposed, including families, workers, and elected officials, can stop it.

Closing the Jacksonville Developmental Center will affect 591 jobs and have a \$47 million economic impact in Morgan County, according to a report filed with the legislature's Commission on Government Forecasting and Accountability (COGFA).

In addition to the direct loss of 420 jobs at JDC, the closing will touch everything in Jacksonville — support businesses, restaurants, grocery stores, entertainment and gas stations included.

Jacksonville would take a \$31 million direct hit, compounded by \$7.3 million in indirect losses and \$8.6 million in induced losses, or those that are the result of people no longer spending money in the community.

"It would affect service industry jobs at Pathway (Pathway Services Unlimited Inc.) and Elm City (Elm City Center) that provide programs and schooling for the developmentally disabled, many of whom are JDC residents," said Jacksonville Mayor Andy Ezard. "People work on the plumbing and heating...gas stations, fast-food, groceries. The more you look into it, it's just a trickle-down effect."

"Our hospitals will be burdened because the doctors on staff (at LDC) won't be there," he said. "And there is a public safety aspect in that we may need to train our police officers on how to deal with developmentally disabled people who would be relocated in the community."

“The business climate here changed dramatically [when Lincoln Developmental Center closed in 2002],” said Michael Maniscalco, executive director of the Lincoln and Logan County Development Partnership. “When the closing was announced, all of a sudden 500 people and their families quit spending.” The local housing market, which was staggering anyway, “completely stopped” and people who were losing their jobs couldn’t get loans.

“That’s what’s going to happen with Jacksonville,” said Cliff McCumber, owner of a Lincoln business. “It’s a no-win situation for everybody.”

‘Huge impact’

Gov. Pat Quinn attempted to close the Jacksonville Developmental Center and other state facilities, including Lincoln Correctional Center, last fall, saying the legislature didn’t appropriate enough money to keep them open. He later found the money to keep them open through June. COGFA — whose recommendation is advisory only — held hearings and ultimately said JDC should not be closed. More hearings are being held this time around, with the next one scheduled for March 7.

In January, Quinn said he would close the Jacksonville center by early October, a move he said would save the state \$11.7 million. A developmental center in Tinley Park also is slated for closing.

Before, several COGFA members said they were concerned that the administration was rushing the closure and didn’t adequately plan for placing the center’s 185 residents in community-based programs.

Ginny Fanning, president of the Jacksonville Area Chamber of Commerce, said the JDC closing “will have a huge impact on us.”

“We are concerned primarily for our residents at the center,” she said. “So many things sadden me about the whole situation.”

She said JDC “has an excellent program.”

State Rep. Jim Watson, R-Jacksonville, said there is still

hope for JDC.

"If enough people in the General Assembly would step up, if members of the governor's own party would step up....," he said. "If we could get a line item in the budget."

Watson said it is upsetting to him that the governor's administration "has shown no indication that they are even concerned about the economic impact on the community. There is no movement to help."

[Read more.](#)

6. Virginia: State officials meet with families to discuss Central Virginia Training Center closing

WDBJ7.com * February 22

State officials are holding meetings around Virginia, addressing concerns about a plan to close four training centers and shift resources to community-based care. One thing many people want to know: where will residents go once the training centers close?

Jill Deiss has been coming to the Central Virginia Training Center for more than 40 years. Her sister Kathy has lived there since she was 11. "She doesn't have control of her body," Deiss said, describing her sister's condition. "She can't talk."

Deiss is one of hundreds who showed up Wednesday for a meeting at the training center.

James Stewart, the state's commissioner on behavioral health, is traveling around the state to answer questions and relieve concerns about recently released plans to close Virginia's four training centers.

"What they're doing is destroying a system and not having equal or better care," said Martha Bryant, a parent whose twin sons have lived at the training center their entire lives.

"I think they'll be dead within days (of the closing)," Bryant said Wednesday. "This is life or death."

"What I want them to do is step forward, and treat what

really are the least among us with the greatest consideration for their future health," Deiss said. "I don't think what they're putting forth to do now is going to do that."

[Read more.](#)

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