

January 4, 2012



Speaking out for people with intellectual & developmental disabilities



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VOR Weekly News Update

News and views for VOR Advocates

Did you receive this as forwarded e-mail? If so, someone thought you would benefit from VOR's information. Please consider [joining VOR](#) and receive this E-News Update publication weekly!

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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message from VOR's Executive Director

Dear VOR Members and Friends:

Thank you to each and every one of you who supported VOR with a year-end gift and encouraged your family and friends to do the same. We are touched by your commitment to VOR and vow, with determination and teamwork, to continue our necessary advocacy to protect the rights of the millions of individuals with intellectual and developmental disabilities, and their families.

VOR is looking forward to working with each of you in 2013.

Throughout the holiday season we received so many very nice notes. As we kick off 2013, this particular letter from a VOR member sums up VOR's unique advocacy voice:

"Dear Julie: There are no words to express our feelings about VOR and the work you are doing. Please know we appreciate VOR making everyone aware of the states' struggles for and against the rights of 'special people' who cannot speak for themselves. Have a Merry Christmas."

2013 marks VOR's 30th Anniversary. With your past and future advocacy and financial support, together we will and must succeed on behalf of all people with intellectual and developmental disabilities.

With gratitude,

Julie M. Huso

Executive Director

[P.S. It's not too late to support VOR. Visit VOR's website for more information.](#)

2. Correction: Apologies for [broken link](#) in the VOR December 21, 2012 Weekly Update. Article reprinted here

Illinois Families Demand Answers

The following is a letter sent to Kevin Casey, director of the Division of Developmental Disabilities in the Illinois Department of Human Services, by Rita Burke and Wayne Ryerson, members of the Jacksonville Developmental Center Closure Advisory Committee. Burke is also the President of the Illinois League of Advocates for the Developmentally Disabled

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a statewide advocacy organization and VOR-affiliate representing residents of Illinois' state-operated developmental centers (ICFs/MR) and their families.

Update: After the letter below was received by Mr. Casey, the previously canceled meeting with the Jacksonville Developmental Center Closure Advisory Committee was rescheduled. The other issues addressed in the following letter continue to be relevant.

December 10, 2012

Dear Director Casey,

As members of the Jacksonville Developmental Center Closure Advisory Committee, we were notified by email on December 3rd that the December 12, 2012 meeting was cancelled due to "scheduling conflicts." As of today, we have not been notified of a rescheduled date.

This is alarming to us because since our last meeting, JDC was emptied and we have been informed that as many as 30 JDC residents were moved wholesale out of the facility to other SODCs as a temporary measure in order to close JDC by an arbitrarily determined date. This is certainly not on the person-centered timeline you promised.

[Read full letter](#)

3. VOR affiliate adds "Deinstitutionalization Nationwide" page to website

Laurie Stengler of the Murray Parents Association (Illinois) has reorganized the group's website to include a "[Deinstitutionalization Nationwide](#)" page with articles and information regarding closures. She also added a separate page for [fiscal issues](#).

Check it out and share via e-mail, Facebook and Twitter. And, while you are at it, please

include VOR's information:

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Fiscal Cliff Deal: Impact on Long Term Care

3. Fiscal Cliff Deal Impacts Long Term Care

The American Tax Payer Relief Act of 2012 [Fiscal Cliff Deal] includes the following two provisions relevant to the LTSS community:

- Repeal of CLASS Program: The implementation of the Community Living Assistance Services and Supports (CLASS) program, passed as part of the Affordable Care Act in 2010, was suspended in October 2011. The Taxpayer Relief Act repeals the program.
- Creation of a Commission on Long-Term Care: Establishes a Commission of Fifteen Individuals (three each appointed by the Speaker, House Minority Leader, Senate Majority Leader, Senate Minority Leader and the President). These individuals will represent different areas of the long-term care continuum and focus on how the Medicare and Medicaid programs, along with the private long-term care insurance market can better meet the needs of individuals. Commission would be comprised of members from the aging and disability communities. Members will have six months to submit their report to Congress on legislative and administration recommendations, but there appears to be no requirement that Congress will need to vote on the findings.

Repeal of the CLASS Program is no surprise, but the creation of a Commission on LTC may be a hopeful sign of future innovation for funding LTSS. On the other hand, there is a long history of Congressional commissions leading to inaction.

Related news: [Fiscal Cliff Deal Repeals Class Act. Creates Long Term Care](#)

Commission

4. Budget – Partial Fiscal Cliff Deal Enacted; Paves the Way for Another Showdown

Capitol Insider (The Arc) * January 2, 2013

After weeks of tense negotiations, both the Senate and House passed a measure to address the series of harmful tax increases and spending cuts that had been set to take effect today. Most of the tax cuts that had been scheduled to take effect have now been permanently extended, while the automatic spending cuts (originally \$1.2 trillion over 10 years) for discretionary programs have been slightly reduced and put off for a two month period.

President Obama is expected to sign the bill as soon as it is presented to him.

The measure represents a partial victory for both the Obama Administration and House Republicans who have been at odds over tax increases and spending cuts to entitlement programs in order to reduce federal deficits. The law will bring in only about \$750 billion in new tax revenue over the next decade, rather than the \$1.6 trillion sought by The Obama Administration. Meanwhile, House Republicans succeeded in raising the threshold on household incomes to \$450,000 that will see a tax increase rather than the \$250,000 that the Obama Administration wanted.

While the newly passed legislation does not include any cuts in benefits for the entitlement programs, this issue is expected to take center stage in the coming weeks as it becomes a bargaining chip in the upcoming debt ceiling negotiations. In the first three months of 2013, additional legislation will be necessary to address other aspects of the nation's fiscal situation. including an increase in the debt

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ceiling, the end of the 2-month extension of the sequester (automatic cuts), and appropriations for the remainder of Fiscal Year 2013. These deadlines will set the stage for additional negotiations between the Congress and the White House. There will be mounting pressure to generate additional revenue and to cut the entitlement programs (Social Security, Medicaid, and Medicare) as well as the discretionary programs (such as housing, education, employment) that people with intellectual and developmental disabilities rely on to live in the community.

Related: [Health Reform and the States: Medicaid Expansion: A Good Deal for States](#)
State News

5. California: Sonoma Developmental Center (SDC): an insiders' perspective

Sonoma (CA) Index-Tribune * December 31, 2012

Katrise Fraud sometimes hesitates when someone asks her where she works.

“There’s nothing like having someone ask you where you work, and you say SDC (Sonoma Developmental Center), and they say, ‘Is that where they rape people?’,” she sighs, obviously annoyed that the actions of a few bad employees have damaged public opinion of the historic institution.

“I wish they understood how hard people work to make things better. I wish they saw all the good work that goes on there.”

Fraud has been a senior psychiatric technician at SDC for 12 years, but has spent more than 25 years working with the developmentally disabled at state centers and places such as Becoming Independent and People First. When she thinks of SDC, she thinks of her fellow staff bending over backwards to track down Beatles swag for a client who loves the British pop band’s music.

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She thinks of teaching a fashion-forward client how to climb a step-stool to access his clothes so he can dress himself. She thinks of the time spent helping another client write to her cousin.

"Her cousin went to China, so we made sure she had a map of China so she could see where that was," Fraund smiles. "People really care about their clients and know what their clients need."

Recent reports of abuse, largely revealed by the investigative journalism of California Watch, have painted a grim picture of the Valley's largest employer. The state has given the center until Friday, Jan. 4, to correct dozens of "deficiencies," including several deemed to pose "immediate jeopardy to resident health and safety." If it does not fix myriad problems identified in reports in July and again in December, SDC stands to lose its federal funding in the Intermediate Care Facility (ICF), which includes a majority of patients and would result in a financial loss of roughly \$117,000 a day.

Fraund admits bad things have happened at SDC, but is quick to point out many other developmental facilities, hospitals and even the Boy Scouts of America have had their scandals, their bad apples.

"These things happen all over the place. There are bad people everywhere, I wish there weren't, but there are," she said. Her voice breaks with emotion when she says, "There are lots of employees there, I don't know what they're all doing."

SDC employs around 1,400 people, including 562 psychiatric technicians who handle all of the

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day-to-day care, from personal hygiene to administering medication to taking clients around the facility for their daily activities. The work is grueling both mentally and physically. The techs are charged with caring for patients with a wide scope of disabilities that impact communication, behavior and cognitive function, and many clients are incapacitated and must be lifted or assisted to interact with their environment.

“We have a lot of techs who are out on workers comp,” Fraund said, explaining that she herself has been off work since March due to a persistent shoulder injury that makes it impossible for her to lift patients. She said state legislators contributed to the failures at SDC. When the state financial crisis hit in 2009-10, budgets were slashed at SDC and other developmental centers, forcing the center to lay off dozens of staff, and enact furlough days and forced overtime.

“You may end up working six overtime days a month,” Fraund said, explaining that there are state requirements on how many staff must be on duty at the 24/7 care facility. So when staff was cut, remaining employees had to pick up the slack, leading to higher rates of injury and general exhaustion. Plus, staff members were more often floated between the nursing unit, where clients have extensive physical needs but fewer behavioral problems, and ICF, where most clients have a dual diagnosis of developmental and behavioral issues.

“The needs of the clients are significantly different on either side,” Fraund said. With layoffs and staff shortages, “You end up with staff who are unfamiliar with those issues, those clients.”

This combination of issues helped create the cauldron where abuse could occur.

“It was iust beina tired and beina short. and

things happen, just like they do any other place,” she said, again emphasizing that the actions of a few do not define the majority. “I really don’t believe you could find people who work harder to serve their clients.”

Fraud said despite what she calls “staff burn-out,” she regularly sees her colleagues go above and beyond the call of duty for their clients. On Christmas, when staffing levels are low, many volunteered to come in to pass out presents and spend time with the clients.

“They don’t have ancillary staff on holidays. So other staff will come in to do stuff like that, because they care,” she said.

The parents at SDC seem to agree. “There are so many wonderful, devoted people there doing a great job for the residents. For a lot of residents it’s the best place, and the only place, they’ve got,” Kathleen Miller, president of the Parent Hospital Association at SDC, said in a previous interview with *The Index-Tribune*.

Fraud insists things are getting better. SDC is hiring again, helping to alleviate the issue of “staff burn-out.” But she said the public could do more to get involved, which would benefit not only the clients’ mental well-being, but also their safety.

“The more eyes that are there, the more people see,” she said. “We don’t want to hide anything. We want people to see us and the good things we do.”

She said she is also hopeful the community supports SDC by contacting members of the legislature and letting them know the cost of budget cuts at high-level care facilities like SDC.

“I’d also like them to write their legislators and remind them of the good work we’re doing, because our guys don’t vote,” she said. “I really do think we are a good place. There are so many positive things that happen there.”

It’s a million tiny things that make a huge

impact, she said. Like taking the time to find out if a non-verbal client likes salt and pepper on his eggs.

If he can't tell you yes or no, then you put some salt on one day. You put pepper on the next day, and you see which one he likes better," she said. "It's helping with the little things, that's what psych techs do every day."

6. New Jersey: Lisa Coscia, named CEO of Hunterdon Developmental Center, was moved by the center's "home-like" atmosphere

Courier News (New Jersey) * January 3, 2013

When Lisa Coscia, the new CEO of the Hunterdon Developmental Center (HDC), first visited the residential treatment center, she was moved by its "home-like" atmosphere and the caring staff, many of whom have spent their entire careers at the center.

"When I first visited the center I was most impressed with the loving environment that the staff has created," said Coscia, who began her new role in mid-December.

Established in 1969, the HDC serves 515 adults ranging in age from 18 to 89 years old with a range of disabilities that include those with developmental and behavioral challenges as well as those with medically complex needs such as patients with tracheotomies and on ventilators.

Residents live in one of 17 cottages or in one of three units in the Health Services Residence on the 102 acre campus located in Clinton. The center provides educational and recreational activities, and an Adaptive Learning Center that offers continuing education in pre-vocational and vocational skills, fine arts, creative dramatics and a greenhouse program.

The Adaptive Learning Center also provides residents with the opportunity to work from their

home through the use of a Work Activity Center (WAC).

Prior to her new role with the HDC, the Tewksbury resident served for 17 years in various capacities, including President, with the Mentor Network, a national network that is comprised of local health and human services providers that offer community-based services.

The Mentor Network serves adults and children with intellectual and developmental disabilities, brain and spinal-cord injuries and other catastrophic injuries and illnesses, as well as youth with emotional, behavioral and medically complex challenges as well as their families.

Coscia is eager to utilize her skills and experience and put them to work for a state-run organization.

“I always had an interest in individuals with developmental challenges. I find great satisfaction in helping people to improve their lives,” Coscia said.

She said one of her greatest challenges going forward will be to learn the inner workings of a state run organization, but she is also excited by the commitment she has encountered among staff and volunteers.

She said she was moved by the fact that the staff has spent additional time with the patients on a voluntary basis, to treat them to special events and excursions.

“I was touched by the extraordinary commitment of the staff. They have established wonderful relationships with the patients and have taken the time to learn about their likes and dislikes,” she said.

Coscia said she believes the center is a very well-run facility.

[Read More](#)

7. More from New Jersey

South Amboy residents support Woodbridge Developmental Center; Residents recommend resolution to keep the state facility open (gmnews.com; December 27, 2012):

Advocates for residents of the Woodbridge Developmental Center (WDC) addressed the City Council on Dec. 19 in hopes that it would pass a resolution in support of keeping the state facility open.

Joanne St. Amand, whose sister Rosemary lives at the WDC, said that family members are against the task force recommendations for a number of reasons, including the fact that other developmental centers are located in South Jersey, which would make visits more difficult. Rosemary, 57, has the cognitive ability of a 3-month-old, she said. St. Amand also said that WDC residents have made a home in Woodbridge.

Other municipalities, such as Woodbridge, Paterson and Totowa, have passed resolution in support of keeping the center open, and advocates have been visiting various municipalities to garner more support.

[Read More](#)

Santa Sighted at New Lisbon Developmental Center; Human Services staff helps St. Nick hand out gifts to residents (State of New Jersey Press Release; December 26, 2012)

Continuing the Christie Administration's Season of Service, Department of Human Services' (DHS) Deputy Commissioner Dawn Apgar and staff today welcomed Santa and his elves at the New Lisbon Developmental Center (NLDC) in Burlington County. St. Nick rode in on a local fire company ladder-truck with a satchel full of donated gifts for the residents. The event is a Christmas Eve tradition, started 35 years ago by the Medford Union Fire Company.

[Read More](#)

Health Care Disparities

8. Health Care A Hurdle For Many With Autism

***Disability Scoop* * December 21, 2012**

Adults with autism are having a harder time accessing health care compared to their typically developing peers, new research suggests.

As a group, those on the autism spectrum are reporting more unmet health care needs, greater use of the emergency room and they are less likely to take advantage of preventive services like Pap smears or tetanus shots than others without the disorder.

Adults with autism also report being less satisfied with communication from doctors and not as comfortable navigating the health care system, according to a new study in the Journal of General Internal Medicine.

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