



Speaking out for people with intellectual & developmental disabilities



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VOR Weekly News Update

News and views for VOR Advocates

To all VOR members and friends, we wish you warm greetings and best wishes this holiday season.

"You always get to the very core of the issues and state conclusions so excellently. Thanks to VOR for giving me access to such outstanding legal representation and all the support to carry this cause forward. You really are exceptional in the best possible way." M.R. (December 2012)

"VOR has always been there for us since our odyssey began in 1996. You and Polly Spare were a godsend when we were budding advocates trying to assist our attorneys in fighting for a continuum of care for our folks." ~ R.K. (December 2012)

VOR is grateful to our friends and advocates for their faithful support throughout each year. Happy New Year!

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Coming up: *There will be no Weekly News Update on December 28, 2012 or January 4, 2013.*

VOR and You

1. VOR's Letter to President Obama Regarding the National Council on Disability's support for deinstitutionalization

VOR * December 11, 2012

Dear Mr. President,

I am writing on behalf of VOR, a national nonprofit organization advocating for high quality care and human rights for all people with intellectual and developmental disabilities (I/DD).

Like you, above all else, I am father.

In my volunteer capacity with VOR, I represent thousands of mothers, fathers, sisters and brothers of citizens with profound I/DD who are receiving high quality, life-sustaining care in licensed facility homes ("ICFs/MR").

[Read More](#)

2. The Chained Consumer Price Index Would Hurt People With Disabilities

The Huffington Post * December 11, 2012

As Washington considers deals to avoid going over the fiscal cliff, there is one proposal that would hurt people with disabilities significantly. Billed as a mere technical change to the annual cost-of-living-adjustment, or COLA, for Social Security, Supplemental Security Income (SSI), and many safety net programs, the so called "chained Consumer Price Index (CPI)" would

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actually be a substantial benefit cut that would [hurt many of our nation's most vulnerable people](#).

The CPI measures inflation and is used to adjust benefits for Social Security, SSI, veterans' disability compensation, and other programs. It is also used to adjust the federal poverty guidelines, which affects eligibility and benefits in [over 30 essential programs](#) including food stamps, Head Start and school meals. When inflation rises, using the CPI to provide a COLA protects the buying power of millions of people across the U.S. including over 56 million Social Security beneficiaries and 8 million SSI beneficiaries. While the CPI may seem like just another Washington, D.C. acronym, it translates into real money in the pockets of many vulnerable Americans.

While cuts from the chained CPI start small, they get bigger every year. For a person receiving the average 2012 Social Security Disability Insurance benefit of about \$1,100 per month, adopting the chained CPI would mean a benefit cut of about \$347 per year (2.6 percent) after 10 years, \$720 (5.4 percent) after 20 years, and \$1,084 per year (8.13 percent) after 30 years. These modest Social Security benefits make up over 75 percent of total income for the vast majority of disabled worker beneficiaries. Similarly, for the lowest 20% of income earners receiving Social Security retirement, those benefits make up about 94 percent of family income.

[Read more](#)

[Write your Federal Officials](#)

3. VOR joins 150+ organizations; calls to protect Medicaid

*Families USA * December 18, 2012*

Dear Member of Congress:

The undersigned organizations, representing a variety of stakeholders including providers and consumers, urge you to not make harmful cuts to Medicaid or change the structure of the program as part of a deficit reduction agreement. There is little room to cut in Medicaid other than the health care services that seniors, people with disabilities, and low-income women and children rely upon.

[Read more](#)

Integrated ICFs/MR

4. Louisiana: Christmas at Pincrest

***The Town Talk* * December 11, 2012 * Editorial by Terry and Glenda Lafleur (Terry is a VOR Board Member)**

As parents, we all have dreams for our children. As parents of mentally disabled children, we are no different. We know our daughter, youngest of three, will never graduate from high school, learn to drive or attend college, and for her our dreams and prayers are a little different. We would like for her to be safe, have her needs taken care of and enjoy a good quality of life. We feel we found that for her at Pincrest Supports and Services in Pineville.

This year we saw her riding in the Pincrest Christmas parade, the first time in her 12 years there. Dec. 7 we saw her in the Pincrest Christmas pageant, something we never thought she would want to do. Pincrest has worked so much with her we now see good changes in her.

Events like the Christmas parade, Christmas play and a beautiful display of Christmas decorations and lights are open to the public. Bring the family to see the beautiful lights.

Budget cuts have hurt Pincrest but not broken the spirit of the employees who work very hard. every day. to ensure that the

residents have a good quality of life. We know, from what we saw for the Christmas play. The residents had parts in the play in the Nativity, singing the "Twelve Days of Christmas," dressing up as elves, reindeer antlers on their heads. But what "brought the house down" was the Michael Jackson song, "Billie Jean," sung by one of the residents. This got all the residents on their feet, those who could, dancing and singing. That was beautiful!

We could see the joy, pride, happiness and feeling of accomplishment in all the residents who took part. They were very proud of themselves. This is what Pinecrest is about.

We all tend to forget that even though they live at Pinecrest, they do have feelings.

I don't know if any invitations were sent out this year, but I will be sending invitations next year to Rapides Parish state representatives, the mayors of Alexandria and Pineville, local religious leaders and news media to come enjoy our Christmas celebration and see the joy and pride on the faces of the residents. We hope you will attend.

As president of our Pinecrest Parents Association and on behalf of all our parents, I want to thank all from the community who took part in making our Christmas parade special and fun. We want to thank the staff at Pinecrest for giving so much of their time so residents, like our daughter, can take part in the activities and have a blast.

Our daughter loves for us to take her riding and she especially likes "Mr. Policeman." My wife and I would like to thank from our hearts, Pineville police Officer Clyde Lemmons for taking time out of his duties to come talk to Jamie, shake her hand and treat her with kindness. Thank you, Officer Lemmons.

Merry Christmas and Happy New Year. God

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bless America.

5. Texas: Horseback riding at Richmond State Supported Living Center

Office of the Governor Rick Perry * Committee on People with Disabilities * November 29, 2012

Numerous state government officials visiting from Austin and nonprofit representatives joined together to cut the ribbon and celebrate an exemplary partnership devoted to providing safe, effective and enjoyable therapeutic horseback riding to people with special needs.

As stated on the certificate presented by State Senator Rodney Ellis's office, the occasion merited "most sincere congratulations ... to SIRE, Houston's Therapeutic Riding Centers and Richmond State Supported Living Center [ICF/MR] on the occasion of celebrating their collaboration."

Reva Williams, of the RSSLC Parents' Association and who had the original dream to build the facility in 1992, brought tears to the eyes of many as she told how horses had made such a remarkable difference in her own daughter's life.

Ileene Robinson, a supporter of activities at RSSLC and who has a relative there, noted, "This partnership is unique because it joins SIRE, Inc. a private facility, with the state facility to bring about one of the most extensive programs being offered in this field. Partnerships like this must be encouraged in more areas to better service the local community of the disabled folks and well as the residents on the campus."

"It is truly a partnership for the benefit of all," says Joelle Devlin, SIRE's Fort Bend site director. And State Representative-elect Stephenson adds, ". . . The SIRE program, as well as the Richmond School itself, are indispensable to our community and its

citizens."

[Read More](#)

[About Sire](#)

6. Texas: Austin living center goes Hollywood

***American-Statesman* * November 21, 2012**

The Austin State Supported Living Center [ICF/MR] has gone Hollywood.

The Central Austin living center for people with intellectual disabilities hosted several days of filming this week for "Trooper," a new television show starring Mira Sorvino and produced by Jerry Bruckheimer. Center residents have been interested in the "Trooper" activity, standing nearby to watch filming and talking to the crew.

Hudgins said the show will pay its way by providing a generous donation to Friends of Austin State Supported Living Center, which raises money for center activities and needs.

This isn't the living center's first time in the spotlight. The facility served as a location for multiple artistic projects in the early 2000s. Over the last decade, there hasn't been much action. But in recent months, the campus has been in demand again, hosting a short movie and a promotion for a video game

"It's been an incredible experience," he said.

[Read more](#)

State News

7. Georgia: Craig Center closing not welcome; VOR speaks out

***The Union Recorder* * December 17, 2012**

MILLEDGEVILLE — A landmark October 2010 settlement between the State of Georgia and the U.S. Department of Justice addressed perceived failures of state hospitals to adequately serve individuals with developmental disabilities and mental illness in the most

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integrated setting appropriate to those needs.

The James B. Craig Nursing Center is next up for the state's battering ram. The skilled nursing center will close by Dec. 31, 2013.

Many former employees, advocates, families and local residents are not convinced the Craig Center closure is the best move.

Legitimate Concern

While some individuals may flourish when moved to a community care home or back with families, more often than not the story isn't as bright. Those with profound intellectual and developmental disabilities cared for at Craig need to stay there, according to two families.

Ann Cox said her daughter Elizabeth, who suffered a brain injury at 2 years old from encephalitis, moved to the Craig Center at age 4. Even as a registered nurse, Cox could not deliver the adequate 24-hour-care Elizabeth demands.

Cox praised the excellent care her daughter has received over the last 24 years.

"Elizabeth can't walk, talk or recognize me. All she knows is if she's well taken care of. Here (Craig Center) they have checks and balances. If you don't do one little thing, somebody is going to catch it. She has never had a bed sore, which is phenomenal for a bed-ridden patient like my daughter," Cox said recently.

Bill Jenkins and wife Faye's 47-year-old son was injured at 25 by brain aneurysm at another facility.

"I would say he has the mind of a 10- to 12-year-old child," Jenkins said. "If you put him out on the street, he will just keep going unless somebody is around to say 'hey turn around and come back.'"

The couple tried caring for their son themselves. but he would act out uncontrollably.

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setting fire to the family home three times, they said.

Central State Hospital Local Redevelopment Authority Executive Director Mike Couch acknowledged the family concern around the impending Craig closure Wednesday. Maybe a section of the population needs to be looked at differently, according to Couch.

CSH authority board member Dudley Rowe echoed the prevailing sentiment. "I'd like to have some satisfaction that we've exhausted all the processes and this is the only solution open to us," Rowe said.

Evaluation of action

Family stakeholders affected by the Craig Center action contend they have largely been in the dark, having no influence on the placement of their loved ones.

Director of Government Relations and Advocacy for [VOR](#), a national organization that advocates for high quality care and human rights for people with intellectual and developmental disabilities, **Tamie Hopp**, said the group in question counts on their families who know them best to arrange adequate care.

"Parents weren't consulted during any part of the process. They were simply told after it was a done deal that their children's homes would close. It's remarkable how uninvolved the families have been," Hopp said.

The move away from institutional treatment is lauded as cost saving, with some estimates claiming more than \$100,000 average savings per patient.

An April 2003 article "[Cost Comparisons of Community and Institutional Residential Settings: Historical Review of Selected Research](#)" findings do not support the position that community settings are less expensive than institutions and suggests staffing issues play a major role in any cost differences.

With the state seemingly resolute facilities like Craig aren't the best option, former teacher at the CSH center, Baldwin County Commissioner Faye Smith, questions whether there are enough places to provide good care to these individuals.

Community-based homes, frequently money-driven, often fall woefully short of the specialized care Craig provides, according to Smith.

Hopp referenced [countless tragedies inside small service settings](#). Though people mean well, few are trained to handle the intense care regimens consumers require.

“What we see when somebody is moved from that intensive care setting into something far less structured, and they are being cared for by well-meaning people who do not have the experience to deal with fragile care needs, it's a recipe for disaster,” Hopp said.

Second Year Review

Independent reviewer Elizabeth Jones published a Sept. 20, 2012 report evaluating Georgia's adherence to mandated community placement. A random sample of 48 developmentally disabled were evaluated.

The report applauds the DBHDD for exceeding numerical targets with home and community based waiver services though it cites recurring problems addressed in the previous year's report.

"The failures to provide meaningful and adequate day programming, to fully monitor health care and to obtain informed consent for psychotropic medications and behavioral support plans again were noted for some of the individuals placed from state hospitals," the Jones report said.

Mentions of rights violations, unsanitary environments and inadequate staffing aren't lost on critics.

“We are working as hard as we can to build capacity,” Howell said. “The current capacity may not exist for the people at Craig, but we have 13 months to figure that out.”

The answer to describe this capacity creation scared Cox. She said an official likened the process to building an airplane in mid-flight.

Hopp and others opposed warn that when something like the Craig closure is quota- and data-driven it won't end well.

With the shuttering of the Craig Center on track for next year, interested parties have little hope to save the place. Jenkins said he thinks the decision-makers should spend a day with people like his son for some perspective.

The people making the decisions need to come down and see or at least have a sympathetic ear to our cause,” Jenkins said. “It's tragic the state of Georgia is doing this to it's tax payers. It's unforgivable what they are doing to these people.”

[Read more](#)

8. Washington State: Report - State ignores group home abuse of developmentally disabled

The Seattle Times *December 17, 2012

A watchdog organization says the state is failing to protect some of Washington's most vulnerable people — those with developmental disabilities who live in group homes. Disability Rights Washington says overworked investigators focus on rule compliance, often overlooking the substance of complaints.

[Read more](#)

9. 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, 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](#)

10. Virginia: Delegate to fight for training center

Galax Gazette * December 6, 2012

While Del. Annie B. Crockett-Stark (R-6th District) has heard that other legislators will file bills to protect the state's training centers from closing, she plans draft her own legislation to help the Southwestern Virginia Training Center in Hillsville which is slated for closure in 2018.

Crockett-Stark says she feels residents should be able to choose to stay in the place that they've called home. "I don't want that choice to be made because they're forced out," she said.

Plus. the distance from Southwestern Virginia

to Chesapeake is prohibitive for residents to be able to visit with their families if they are transferred.

"I'm going to carry the bill to the floor and have the conversation that we need," she said. "I don't think those doors should close. Those people can't speak for themselves so we need to speak for them.

Research News

11. A Tense Compromise on Defining Disorders

**The New York Times * December 10, 2012
(Commentary on DSM-V)**

This month, the American Psychiatric Association announced that its board of trustees had approved the fifth edition of the association's influential diagnostic manual [DSM] — the so-called bible of mental disorders — ending more than five years of sometimes acrimonious, and often very public, controversy.

The committee of doctors appointed by the psychiatric association had attempted to execute a paradigm shift, changing how mental disorders are conceived and posting its proposals online for the public to comment. And comment it did: Patient advocacy groups sounded off, objecting to proposed changes in the definitions of depression and Asperger syndrome, among other diagnoses. Outside academic researchers did, too. A few committee members quit in protest.

The final text, which won't be fully available until publication this spring, has already gotten predictably mixed reviews. "Given the challenges in a field where objective lines are hard to draw, they did a solid job," said Dr. Michael First, a psychiatrist at Columbia who edited a previous version of the manual and was a consultant on this one.

Others disagreed. "This is the saddest moment in my 45-year career of practicing, studying and teaching psychiatry," wrote Dr.

Allen Frances, the chairman of a previous committee who has been one of the most vocal critics, in a blog post about the new manual, the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders, or DSM5.

Yet many experts inside and outside the process said the final document was not radically different from the previous version, and its lessons more mundane than the rhetoric implied. The status quo is hard to budge, for one. And when changes do happen, they are not necessarily the ones that were intended.

The debate over autism was furious.

From the outset, the committee intended to tighten the definition of autism and simplify it, eliminating related labels like Asperger syndrome and “pervasive developmental disorder not otherwise specified,” or PDD-NOS. The rate of diagnosis of such conditions has exploded over the past decade, in part due to the vagueness of the definitions, and the committee wanted to draw clearer boundaries.

It proposed a single “autism spectrum disorder” category, with stricter requirements.

Some outside researchers raised concerns and autism groups reacted immediately, fearing that the change in the diagnosis would deny services to children and families who need them.

A new, streamlined definition was approved, but with language that took into account a person’s diagnostic history. “It’s explicit that anyone who’s had an Asperger’s or autism or PDD-NOS diagnosis before is now included,” said Catherine Lord, a committee member who worked on the new definition and who is director of the Center for Autism and the Developing Brain in New York. “Essentially everyone gets in.”

[Read More](#)

Quotable

“We’re protecting civil liberties at the expense of health and safety,” says Doris A. Fuller, the executive director of the [Treatment Advocacy Center](#), a nonprofit group that lobbies for broader involuntary commitment standards. “Deinstitutionalization has gone way too far.” ([Washington Post, December 17, 2012](#)).

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