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Speaking out for people with  
intellectual & developmental  
disabilities



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**Reminders:  
Help VOR Grow!**

February 7, 2014

## VOR Weekly News Update

*News and views for VOR Advocates*

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[Registration is now open for VOR's Annual  
Conference and Initiative. Details are  
available on VOR's Website.](#)

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#### VOR and YOU

##### **1. Facebook 500! Help VOR reach 500 Likes**

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For the past year, VOR has been working on awareness and outreach. Our efforts have resulted in many more [Twitter](#) followers and an ever growing "fan" base on [Facebook](#). Just this week, we saw a jump in the number of individuals and advocates interested in VOR – so much so we are approaching 500 Likes!

**Can you help us spread the word?** Please share [VOR's Facebook page](#) with your friends. We are now at 417 Likes. **Help us reach 500+!**

##### **2. Introducing Ellen Laurence, VOR's new Colorado State Coordinator**

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VOR is pleased to welcome Ellen Laurence, VOR's newest [State Coordinator](#).

Representing the State of Colorado, Ellen is the founder and spokesperson for the recently

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formed "Save the Colorado Regional Centers."

Ellen, a registered nurse, and her husband, Norm, an architect, live in Greeley, Colorado, and have three children. Their youngest, Juliana (Annie), is 32 years old and has multiple diagnoses. She has been a resident at Wheat Ridge Regional Center (Colorado) since 1995.

As a long-time member of VOR, Ellen knew she was not alone in her ongoing battle to save Annie's home. Upon founding the "Save the Colorado Regional Centers" organization, she reached out to VOR almost immediately.

"I feel passionately that there must be a continuum of residential services for persons with I/DD," said Ellen. "I am certain that parents know what is best for their children, and to that end we should be full participants/stakeholders at the 'table' and our opinions be respected and valued. It is SO reassuring to know that VOR is with and we are not alone in this on-going fight."

Stepping up her involvement now was the right and necessary thing to do, said Ellen.

"If not us, then who?"

### 3. Annual Conference Speaker

**Feature: Meet Kim Stagliano – Mother, Advocate, Speaker and Author**

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VOR will be offering Speaker Features over the next couple of weeks. The first, featuring Kim Stagliano, follows. For more information about our Annual Conference and Initiative, including [registration](#) and [sponsorship opportunities](#), please visit our [website](#).

VOR is pleased to introduce you to [Kim Stagliano](#), our featured dinner speaker at the 2014 VOR Annual Conference on June 8, 2014 in Washington, D.C.

A nationally recognized autism advocate and

lively speaker, Stagliano will present “*Is 50 Nifty with 3 Special Needs Children?*” for VOR Annual Conference participants. Although autism typically affects boys 4 to 1 over girls, Stagliano is in the unique position of having three daughters with full-blown autism, which has made her and her family a focus of national media attention. She is author of the memoir [All I Can Handle I'm Not Mother Teresa: A Life Raising Three Daughters with Autism](#) and the novel [House of Cards](#).

Stagliano also serves as Managing Editor of [www.ageofautism.com](http://www.ageofautism.com), the nation’s first daily web newspaper about the autism epidemic, and she writes for *The Huffington Post* and *The Autism File Magazine*. She speaks at national conferences and has appeared on *Good Morning America*, *ABC News*, numerous morning shows, *Fox News*, in *The Chicago Tribune*, *The National Catholic Register*, and on blogs around the world.

In her presentation for VOR, Stagliano will relate her experiences as a mother and advocate who, like VOR members, has dedicated her life to the daily and future well-being of children with profound disabilities. In the spirit of “we’re all in this together and together we are stronger,” Stagliano will give a motivating, lessons-learned in life and advocacy, presentation.

A former sales and marketing executive, Stagliano lives in Connecticut with her family.

## **STATE NEWS**

**4. Kentucky: State Senate Judiciary Committee approves bill that would create an adult protection registry**

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*Lexington Herald-Leader* \* February 6, 2014

FRANKFORT — A Senate Judiciary

committee approved a bill Thursday that would create an adult protection registry.

Senate Bill 98, sponsored by Sen. Sara Beth Gregory, R-Monticello, would allow individuals, their families and care providers to see whether the Cabinet for Health and Family Services has substantiated allegations of abuse involving a prospective employee.

The bill would require agencies that provide caretakers for vulnerable adults to ask whether potential employees, contractors and volunteers were on the registry.

In order for someone to be placed on the registry, the cabinet would have to determine through a preponderance of evidence that a caretaker had been abusive. The caretaker would have to be given an opportunity for an administrative hearing and exhausted all appeals.

Under the state's current system, Gregory said, there's no way for loved ones to know about previous allegations.

[Read more, comment and share](#)

**Additional information is about this Kentucky bill is in [VOR's Weekly E-News Update, January 31, 2014](#)**

## **5. California: Developmental Center families are worried**

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***The Kenwood Press* \* February 1, 2014 \* Opinion by Kathleen Miller, president, Parent Hospital Association (PHA)**

Sonoma Developmental Center families and friends are worried. We listened to the task force on the future of developmental center hearings. We hear the ongoing diatribe against developmental centers. We hear the call for closure. We hear the need to save the state

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money. Also, we know our own histories.

[Read more, comment and share](#)

## **6. Kansas: State Becomes First to Outsource Disability**

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*Disability Scoop* \* February 4, 2014

Starting Saturday, long-term Medicaid services for Osipik and about 8,500 others with developmental disabilities were moved into a managed care program run by private insurers. People with physical disabilities had been moved into KanCare last year when the program started.

Three companies — Amerigroup, Sunflower State Health Plan and UnitedHealthcare Community Plan — are charged with improving health outcomes while limiting the growth of health care costs.

Kansas is the first state to place its population of people with developmental disabilities with managed care companies, said Gary Blumenthal, president of the Association of Developmental Disabilities Providers in Massachusetts.

“There will be a tremendous number of eyes focused on Kansas to see if this is going to be a successful initiative,” said Blumenthal, a regional director of Kansas Social and Rehabilitation Services a decade ago.

[Read more, comment and share](#)

## **7. Washington State: ActionDD responds to biased DD Services State Audit**

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**Paul Strand, President, [Action DD](#) \* January 29,  
2013**

**Background:** *Washington State performed a State Performance Audit of the Developmental Disabilities Administration (DDA)*

*The audit explored two primary questions: (1) Does Washington's DD Program provide effective services and supports for people with developmental disabilities? and (2) What steps could the State take to improve its ability to provide effective services and supports for people with developmental disabilities? Advocates for a full array of residential options, from small residential settings to licensed facility based care have found serious flaws with the audit. One example, a recent letter from Action DD (a VOR affiliate) is below.*

**To: Chair Randi Becker, Washington State Senate Health Committee**

Dear Senator Becker,

You asked what we thought was wrong with the recent DD services audit. In a nutshell, the audit:

- Fails to utilize accurate or complete information in looking at the acuity (support needs) of DDA clients.
- Uses only DDA provided cost data which does not include money spent by other agencies or community vendors, thus making the cost of most services look artificially low.
- Medicaid Financial Management Reports are ignored.
- Pits community based services against RHC services.
- Was contracted out to a vendor with a known bias against institutions. For example, an audit presentation to the JLARC showed a picture of a multi-storied brick building in Kansas and called it an RHC.
- Unfairly portrays RHCs as expensive and restrictive and suggests closing them.
- Selectively quotes the Olmstead Decision to say that people should live in the "least restrictive environment" not in an RHC, when Olmstead also says, "The ADA is not reasonably read to impel states to phase out institutions, placing patients in need of close care at risk."
- Fails to recognize that a percentage of people with developmental disabilities require, either on a permanent or temporary basis, the

services provided by our RHCs.

- Involved no health care providers to assess need, nor did any of the audit staff have health care credentials. RHCs are medical facilities.

The audit was right about our need to provide services to a large unserved population, as was brought to light by the legislative task force report of 2012. They were wrong to say closing RHCs would provide the resources to fund the unserved.

We at Action DD believe the audit is flawed and should not be used as a basis for legislation.

Sincerely,  
Paul Strand, President  
[Action DD](#)  
Washington State

[Read related letter by ActionDD](#)  
[See related information at Because We Care](#)

#### **8. Washington State: Some mental-health officials oppose commitment bill**

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***The Seattle Times* \* February 3, 2014**

Parents of a 28-year-old man fatally shot by Seattle police last summer testified for a bill to make it easier to commit a relative for mental-health treatment in Washington. They encountered opposition from an unexpected quarter - mental-health community itself, including Disability Rights Washington (P&A).

The back-to-back morning hearings featured plenty of support from lawmakers and a steady stream of parents urging passage of the proposal.

But some advocates expressed concerns that the changes would put more stress on an overwhelmed and underfunded mental-health system — especially because the law is already set to change in July to make it somewhat easier to commit citizens.

The opposition triggered tension, especially in the House Judiciary Committee.

“I got to tell you, I’m shocked that we’ve got advocates of mental-health organizations here opposing this bill that would make it easier to get those in need of treatment into treatment,” state Rep. Jay Rodne, R-North Bend, said at one point to applause from the crowd. “I mean, I expected that from the criminal-defense bar, but from the mental-health professionals — I am shocked.”

[Read more, comment and share](#)

### **9. Tennessee: Disabilities website helps doctors communicate with, treat patients; Site also meant as resource for patients, caregivers**

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*The Tennessean* \* February 2, 2014

Many doctors have little or no experience treating patients who have intellectual disabilities — people who may not be able to articulate how they feel or to fully understand a doctor’s questions.

A new website — [www.iddtoolkit.org](http://www.iddtoolkit.org) — aims to provide primary-care physicians with tools for communicating with and treating patients with intellectual disabilities, defined as having an IQ of 70 or below.

The website was created by the state Department of Intellectual and Developmental Disabilities, the Vanderbilt Kennedy Center for Excellence in Developmental Disabilities, and the Boling Center for Developmental Disabilities at the University of Tennessee.

The website gives doctors guidance in how to interact with patients and assess their physical health and behavioral issues. The site provides checklists for problems associated with specific diagnoses such as Down syndrome.

It also is intended to be a resource for people with intellectual disabilities and their caregivers, who can share the guidelines with physicians or follow the tips for communicating with medical professionals, said Dr. Thomas Cheetham, director of the Office of Health Services for DIDD.

[Read more, comment and share](#)

[Visit VOR's "Medical Resources" section of our website](#)

### **NATIONAL NEWS**

#### **10. Medicaid's exclusion of dental patients with special needs**

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***Mouthing Off, the Blog of the American Student Dental Association \* by Sarah Usher \* February 3, 2014***

Currently, those with an intellectual disability are the most underserved medical and dental population (MUP). Volumes of [documentation](#) support this evidence with access to dental care as the number one health problem people with disabilities face.

The U.S. Department of Health and Human services maintains a formula for distinguishing w MUPs. When calculated for people with ND/ID, the formula proves that this population is deserving of the distinction and the medical and dental resources that follow (read more on this argument in this journal article published in [Special Care in Dentistry](#) and this [press release](#) from the American Academy of Developmental Medicine and Dentistry).

Dental coverage offered to adult individuals with ND/ID through Medicaid varies within each state because dental services are not a federally mandated benefit for adults (visit [Medicaid.gov](http://Medicaid.gov): [Medicaid Mandatorv](#)

[Benefits](#)). There are few states that provide [Medicaid Adult Benefits for dentistry](#) and may only provide emergency services (extraction).

[Read more, comment and share](#)

### **Quotable**

*"The most important thing in the Olympic Games is not winning but taking part; the essential thing in life is not conquering but fighting well. ~ Pierre de Coubertin*

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### **Calendar Reminders:**

**Tuesday, March 25, 2014**

[AHCA/NCAL's fifth annual "ID/DD Residential Services Providers Hill Fly-In."](#) Questions? Dana Halvorson, [dhalvorson@ahca.org](mailto:dhalvorson@ahca.org).

**June 8, 2014**

### **VOR 2014 Annual Conference and Initiative:**

*"Making it Happen: Reforming Policy and Law in Support of Person-Centered Quality and Choice"; Hyatt Regency, Washington, D.C.*

### **Register today!**

**Week of June 9, 2013**

**VOR 2014 Congressional Initiative:** Families and advocates visit Capitol Hill.

**Sunday, October 5, 2014**

American Health Care Association's 2014 ID/DD Residential Services Day during AHCA/NCAL's 65th Annual Convention & Expo at the Gaylord National Harbor just outside of Washington, DC. Registration will open in Spring 2014.

### **Archives**

**\*Social Media Strengths: Using Facebook and Twitter to Advance Your Cause (VOR, July 2013).** [Visit VOR's website for a copy of the powerpoint presentation and an audio of the](#)

[event.](#)

\* **How Congress Works Webinar: [Recorded - Listen Here.](#) Tuesday, April 23, 2013 - 12:00 pm central / 1:00 pm eastern. How Congress Works: The Basics. Hosted by Peter Kinzler and Larry Innis.**

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