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June 21, 2013



Speaking out for people with  
intellectual & developmental  
disabilities



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**Reminders:  
Help VOR Grow!**

## VOR Weekly News Update

*News and views for VOR Advocates*

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VOR and You

**1. Sign a Member [Petition](#) in Support of Sonoma Developmental Center (California)**

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**Source: Mary O'Riordan, VOR Board Member-Elect**

There is a Task Force in place to determine the future of the remaining developmental center for the care and services for developmentally disabled people - please make sure the Sonoma Developmental Center is not on the table to be closed as this leaves all northern California with no safety net for our most severe, frail, developmentally disabled people.

Please sign my [petition](#) to the California State House, the California State senate, and Governor Jerry Brown calling for their support of Sonoma Developmental Center, a state operated Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID).

**[You can read and sign my petition here](#)**

Thank you!

**2. Standing up for the rights of people with intellectual disabilities, VOR volunteer leaders and advocates take their concerns to Congress**

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**VOR \* June 17, 2013 \* For Immediate Release**

## Reminders: Help VOR Grow!

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WASHINGTON, D.C. – From June 8 - 12, nearly 70 volunteers representing 22 states attended the VOR Annual Conference and Initiative in Washington, D.C.

VOR is a national family/guardian organization advocating for high quality care and human rights for all people with intellectual and developmental disabilities (I/DD). Attendees were mostly families and some caregivers of people with profound intellectual disabilities.

VOR members and advocates attending this annual event were briefed on important issues affecting people who are medically fragile and are fully dependent on 24-7 care for survival.

Family advocates then visited all members of Congress. Other key federal agencies within the Administration also received VOR's presentation.

Americans with severe and profound intellectual disabilities are being seriously threatened by closure of their homes by reduction in budgets and a shift of basic government philosophy that dictates all people are allegedly better served living in a community setting, even if needed medical and personal care is reduced to a point where lives are being threatened. In addition to protesting home closures, VOR seeks community-based standards to address current deficiencies.

“We had a very productive week in Washington, D.C. and left committed to the challenges that impact our children,” said Ann Knighton, President of VOR. “Generally, Members of Congress are empathetic to our concerns. It's hard to argue against individual choice, family involvement and quality care across all settings. Our challenge now is to turn this empathy into action on behalf of all people with intellectual and developmental disabilities.

**3. THANK YOU CONFERENCE SPONSORS**

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## Reminders: Help VOR Grow!

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Without the financial support of generous individuals, organizations and corporations, the VOR Annual Conference and Initiative would not be possible.

We are grateful to all [sponsors](#) for recognizing the importance of VOR's pinnacle event and helping to make it happen year after year. We are especially grateful to *EP (Exceptional Parent) Magazine* for its partnership this year in helping to reach out to Sponsors and for offering advertising options for our top financial contributors: The Parent Hospital Association of Sonoma Developmental Center, the American Health Care Association/National Center for Assisted Living, and Patrons of Partlow. [Click here to see all of the 2013 VOR Annual Conference and Initiative Sponsors.](#)

### **4. Interested in serving on a VOR National Committee? VOR now accepting Committee Interest Forms**

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#### **VOR \* June 21, 2013**

VOR's strength rests on the time, talent and ingenuity of our board and committee members, with much of the work getting done in committee.

VOR has a number of standing committees and we'd like to make sure that VOR members have the opportunity to indicate your interest to serve on the committee(s) that reflects your interests and availability. We are also seeking candidates for VOR's Board of Directors for the term beginning July 1, 2013.

[A volunteer form and descriptions of each VOR Standing Committee and form to indicate in your interest in serving on a VOR Committee and/or the VOR Board of Directors is available here.](#)

Forms can be returned to:

Sybil Finken, VOR Immediate Past President,  
finkensrc@aol.com: Fax: 605-399-1631

U.S. Mail: VOR, P.O. Box 1208, Rapid City, SD  
57709

Thank you for your consideration.

Sincerely,

*Ann Knighton*, VOR President

**5. Providers address the need to standardize care  
across all settings serving people with disabilities  
at national convention**

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**VOR \* June 17, 2013**

WASHINGTON, D.C. – On June 9, Terry Kopansky, Executive Director of Mur-Ci Homes, Inc., a care provider for people with developmental disabilities in Antioch, Tennessee, moderated a panel of experts who discuss proven strategies for delivering high quality care to this vulnerable population. The panel discussion, featuring Ralph Kennedy of Tennessee Family Solutions (Nashville), Renee Naylor of Westcare Management (Oregon), and Brad Whitehead of Lanterman Developmental Center (California), was part of the national convention of VOR, a nonprofit advocacy organization.

“It was an exceptional panel of experts discussing their life work,” remarked Kopansky. “As providers, we value quality care above all us. Sadly, not all providers operate with the same values. This panel discussion was a first step toward considering how we can ensure consistent quality across all settings for the people we represent.”

Kopansky, who was recently elected to the VOR Board of Directors, expressed hope that this conversation was only the beginning.

[Read More](#)

**6. Know a fabulous State Legislature Staffer? The  
National Council on State Legislatures is seeking  
nominations for its Executive Committee**

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**To: All Interested Legislative Staff**

**From: Patsy Spaw, NCSL Staff Chair**

**Date: June 10, 2013**

**Re: 2013 Legislative Staff Nominating Committee**

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NCSL's 2013 Legislative Staff Nominating Committee is seeking nominations for legislative staff to serve on the 2013-2014 Executive Committee as Staff Vice Chair (Deadline: July 1) or at-large members (Deadline: July 15, 2013). The task of the 2013 Legislative Staff Nominating Committee, which meets at the NCSL Legislative Summit in Atlanta, Georgia in August, is to nominate a slate of 16 members and three officers of the NCSL Executive Committee for Conference Year 2013-2014.

[Click here for information about the three vacancies, deadlines and submission requirements.](#)

**7. SAVE THE DATE: VOR SOCIAL MEDIA**

**WEBINAR:** An overview of Twitter and Facebook, Wednesday, July 17, 2013 - 12:00 pm central / 1:00 pm eastern

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Registration details coming soon. Cost: Free.  
**State News**

**8. New Jersey: Families suing Christie over plan to close state institutions win lawmaker's support**

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*The Star-Ledger* (Trenton, NJ) \* June 19, 2013

State Sen. Richard Codey (D-Essex) said he is introducing a resolution Thursday to show support for the families who filed a class-action lawsuit against the Christie administration in the hope they can halt a plan to close two institutions for people with developmental disabilities by 2017.

[Read more](#)

[Read about the lawsuit](#)

[Read the Complaint](#)

[View Video](#)

**9. Texas: Family supported equal information access bill signed by Governor Perry**

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HB 2276 passed the Texas Legislature without opposition and. on June 14. was signed

by the Governor.

This equal information-access bill simply requires each mental health and mental retardation authority in each Texas County (as the gatekeeper to all services) to give each person a brochure containing information about all programs available including the state supported living centers across Texas and which centers have openings nearest them. The State of Texas will offer a brochure that lists all options. The brochure will be signed by case managers and individuals, or their legal representatives, to ensure that information about all services is being presented and represented in a fair and equitable manner. In the past, [individuals and their families were often not made aware of available services at state supported living centers.](#)

[Read more](#)

[Copy of HB 2276](#)

[Video: Andrew's Story: One families' story of struggle to find adequate services for their son; finding home and care at State Supported Living Center](#)

**10. National: More of us are caregivers, and it's taking a big toll on our lives**

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***Kansas City Star \* June 20, 2013***

A national survey being released today by the Pew Research Center shows a growing number of Americans now find themselves in similar situations. According to the study, 39 percent of Americans have provided at least some unpaid care for an adult or child with significant health issues, up from 30 percent just since 2010.

Most of the caregivers surveyed in the study take care of an adult, while a much smaller number care for a child with significant health issues.

The percentage of people caring for family members will likely continue rising, according to

the study. America's population is aging, and three-quarters of people 65 and older suffer from chronic health problems.

[Read more](#)

## **11. National: Health Disparities and People with Disabilities Health Disparities and People with Disabilities**

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**Disability Blog \* June 12, 2013 \* By Guest Blogger Stanley Holbrook, President and CEO of Three Rivers Center for Independent Living and Diversity Chair of National Council on Independent Living**

In spite of startling evidence of health disparities among people with disabilities and the inherent costs to treat preventable conditions, current federal law does not consider individuals with disabilities as a "medically underserved population." It also does not include disabilities under requirements for cultural competence and fails to recognize disabilities under any federal program that addresses health disparities.

Overall, people with disabilities have been reported to experience fair or poor health approximately four times more than their peers without disabilities. In addition, a disproportionate percentage of people with disabilities experience the social determinants of poor health (CDC Health Disparities and Inequities Report United States 2011).

There are three dimensions of health intervention: Access and quality of health services; addressing the social determinants of health; and addressing the social determinants of equity.

[Read more](#)

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**Calendar Reminders:**

**\*SAVE THE DATE: VOR SOCIAL MEDIA**

**WEBINAR: An overview of Twitter and Facebook, Wednesday, July 17, 2013 - 12:00 pm central / 1:00**

pm eastern. Cost: Free. Registration details coming soon.

\* [Recorded - Listen Here. Tuesday, April 23, 2013 - 12:00 pm central / 1:00 pm eastern](#)

**FREE WEBINAR:** How Congress Works: The Basics. Hosted by Peter Kinzler and Larry Innis.

\* [Sunday, June 9, 2013](#)

VOR Annual Conference \* Washington, D.C. [Registration 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.](#)

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