

[Click to view this email in a browser](#)

August 23, 2013



Speaking out for people with
intellectual & developmental
disabilities



www.vor.net



/VOR



@VOR_NET



info@vor.net

**Reminders:
Help VOR Grow!**

**Make a Lasting
Impact with a
Will Bequest**

Our apologizes for our oversight.
This version includes [Real Choices in Care Blog link](#).

VOR Weekly News Update

News and views for VOR Advocates

[About VOR](#) * [Refer a Friend](#) * [Donate](#)

Table of Contents

VOR and You

1. Reminder [Have you taken action? Calling for DD Act Investigation, Reform and Reauthorization has never been easier AND NECESSARY!](#)

State News

2. California: Families urge keeping Sonoma Developmental Center open

3. New Jersey: State saves sheltered workshops for adults with developmentally disabilities

4. New Jersey: Christie Administration's Interpretation of a U.S. Supreme Court Decision Questioned

Federal/National News

5. Feds Reverse Course On Disability Provision Of Affordable Care Act

6. How ideology trumps logic in the care of the developmentally disabled

Quotable

Calendar Reminders

VOR and You

1. Reminder: [Have you taken action? Calling for DD Act Investigation, Reform and Reauthorization has never been easier AND NECESSARY!](#)

If not us. who?

VOR.net:
Your one-stop
advocacy
resource

A [blogger in Wyoming](#) wrote recently: "The developmentally disabled, their families and advocates should flood the Capitol Building. They should occupy the rotunda of the building, filling it with the faces of the people who will suffer the impact of the choice the legislature made. These politicians don't want to come face-to-face with their choices. They are counting on us remaining in the shadows, fearful and voiceless. Don't let them get away that easy."

If not us, who?

[Take Action and Share with Others](#)

State News

2. California: Families urge keeping Sonoma Developmental Center open

***The Press Democrat* * August 19, 2013**

People who have loved ones living at Sonoma Developmental Center lobbied a state task force in Sacramento Monday to keep the troubled facility open, saying it's better than the alternative of community-based care.

"The next 25 years of Mark's life should not be spent with caregivers who are recruited from Craigslist and promised a wage of \$10 an hour," Diane Halcromb said of her 50-year-old brother, Mark Dunkelberger, who has been a resident of the Eldridge facility since 1988.

Halcromb was among several family members to address the task force, which is weighing California's role in providing services to 260,000 of the state's disabled residents, including 1,510 who reside in one of the state's four remaining developmental centers. With nearly 500 residents, Sonoma is the largest of those facilities.

**Reminders:
Help VOR Grow!**

**Make a Lasting
Impact with a
Will Bequest**

**VOR.net:
Your one-stop
advocacy
resource**

Fighting through tears, Marcella Harris described for the panel the struggle to find quality care for her autistic 17-year-old son. She said she finally obtained a court order for him to be placed at Sonoma, but not before he may have permanently blinded himself, the result of him banging his head against walls and repeatedly hitting himself.

She now fears for his future with the court order expiring and his return to a group home in San Jose.

Harris told the task force that “there's something wrong in the safety net. There's a hole in it.”

[Read more, comment and share](#)

3. New Jersey: State saves sheltered workshops for adults with developmentally disabilities

***Courier Times* * Updated August 12, 2013**

The state's sheltered workshop program will continue after participants and their families rallied the Legislature to keep it in place as an option for adults with disabilities to do meaningful paid jobs in safe and supportive workplaces despite their challenges.

Earlier this year, the New Jersey Department of Human Services' Division of Developmental Disabilities announced plans to begin phasing out and defunding sheltered workshops, including a program at the nonprofit Burlington County Occupational Training Center in Burlington Township, in favor of reformed and expanded supportive work programs that would focus on moving the population into competitive employment in the community.

The reform was in keeping with New Jersey's commitment as an “Employment First” state that recognizes that “competitive employment in the general workforce is the first and preferred post-education outcome for people with any type of disability.” While providers, including the OTC.

applaud the shift in focus and would still deliver the services, they argued that the state shouldn't eliminate all other options. The plan to defund the sheltered workshops immediately met with opposition from advocates, program participants and their families in Burlington County and elsewhere in the state. About 160 workers would have been affected in the county's OTC program.

The issue of sheltered workshops, including fair pay and meeting the needs of workers with developmental disabilities, is part of a continuing national debate.

[Read more, comment and share](#)

4. New Jersey: Christie Administration's Interpretation of a U.S. Supreme Court Decision Questioned

***The Alternative Press* * August 21, 2013 by Salvatore Pizzuro**

The proposed closing of two of New Jersey's Developmental Centers at Totowa and Woodbridge has elicited much controversy, debate and protests from the families of the residents of the centers. A joint legislative hearing was held at Montclair State University in February 2013 in order to collect testimony regarding the proposed closures. At the hearing, sponsored jointly by the Senate Committee on Health, Human Services and Senior Citizens and the Assembly Committee on Human Services, more than 600 people assembled to protest the proposed closings.

One of the issues that is rarely mentioned is the current State Administration has falsely cited the tenets of a United States Supreme Court decision in order to support their plan to deinstitutionalize.

Nevertheless, the Olmstead decision does not mandate that all people with developmental disabilities should be transferred to the

community, nor does it state that the larger institutions should be closed. All people, including those with disabilities, are unique and have different needs. We need a variety of settings from a continuum that provides a variety of services.

[Read more, share and comment](#)

Federal/National News

5. Feds Reverse Course On Disability Provision Of Affordable Care Act

***The Oregonian* * August 19, 2013 (via *Disability Scoop*)**

Federal officials have reversed course on a new provision of the Affordable Care Act that would have largely barred guardians from serving as paid caregivers for adult children with developmental disabilities.

Officials with the Oregon Department of Human Services said Friday that federal officials have agreed to work with the state to develop “the right processes” to allow guardians — oftentimes relatives — to continue as paid caregivers. It’s unclear yet what those processes will be, said Patrice Botsford, director of developmental disabilities services for the department.

“We’ll be working on it next week,” she said. “We will do it as rapidly as we possibly can.”

The news comes as a relief to parents such as Deana Copeland, who feared the provision could have forced her to place her 22-year-old daughter in foster care. Her daughter, Andrea Hood, suffers from cerebral palsy, spina bifida and autonomic dysreflexia, a potentially life-threatening condition and requires

around-the-clock care.

Copeland is both Hood's legal guardian and paid service provider, for which she receives \$1,400 a month.

"I feel elated, but it's not done," said Copeland, a Cornelius, Ore. resident who has cared for Hood since she was born. "We have to make sure that families aren't torn apart."

The purpose of the federal provision is to protect against the possibility of financial fraud, since the guardian who develops a care plan has the ability to hire himself or herself as the paid caregiver.

However, Oregon has allowed guardians to be paid caregivers for more than 10 years under various federal waivers, reportedly without issue.

The new provision is part of the K Plan, a Medicaid state plan option under the Affordable Care Act. Oregon is the first state to implement the plan, which emphasizes home and community-based services.

Disability rights advocates and state officials have been fighting the new provision, saying it could restrict flexibility and choice for the 455 Oregon families where the guardian is the paid caregiver.

Although Copeland is ecstatic about the prospect of continuing as her daughter's guardian and caregiver, she's also confused and exhausted over the procedural hurdles of the new law.

"Every can of worms I open, I feel like there's just another can of worms," she said. "All of our energy goes into learning about our child's medical needs. To try and learn all the politics involved in it too? It's just

too much for some of us.”

[Read more, share and comment](#)

6. How ideology trumps logic in the care of the developmentally disabled

***Real Choices in Care Blog* * August 20, 2013
by David Kassel**

When public policy is based on ideology, it is usually not based on logic or common sense.

Today’s anti-congregate care ideology is a case in point. This ideology is held by top administrators in agencies ranging from the Centers for Medicare and Medicaid Services to the Department of Justice, who act in the name of choice and personal control, but actually end up restricting both.

According to the ideology, any care setting for the developmentally disabled that serves more than two or three disabled people at one time is now considered to be “segregated” because it separates those people even momentarily from the “community.” No consideration is given here to the consequences of basing policy on this ideology or what the recipients or their families want or think.

[Read more, comment and share](#)

Quotable

“Life isn’t about how to survive the storm, but how to dance in the rain.” ~ Unknown

=====

[Calendar Reminders:](#)

***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.
* **AHCA/NCAL to host Intellectual and Developmental Disabilities (ID/DD) Day – October 6, 2013.** [Details online.](#)

VOR
836 S. Arlington Heights Rd., #351
Elk Grove Village, IL 60007

Tel: (605) 399-1624
Toll Free: (877) 399-4867
Fax: (605) 399-1631
Email: info@vor.net

JOIN VOR. DONATE TO VOR. MAKE A DIFFERENCE

If you no longer wish to receive these emails, please reply to this message with "Unsubscribe" in the subject line or simply click on the following link: [Unsubscribe](#)

[Click here](#) to forward this email to a friend

VOR
836 S. Arlington Heights Rd.
#351
Elk Grove Village, Illinois 60007
US

[Read](#) the VerticalResponse marketing policy.

