

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

November 1, 2013



Speaking out for people with
intellectual & developmental
disabilities



www.vor.net



/VOR



@VOR_NET



VOR4Choice



info@vor.net

**Reminders:
Help VOR Grow!**

VOR Weekly News Update

News and views for VOR Advocates

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

Table of Contents

VOR and You

1. VOR's Julie Huso to Address Wyoming Families
2. VOR Submits Testimony In Response to California's Proposed Secured Perimeter Regulations
3. VOR in the states: A recap

State News

4. **New Jersey:** Woodbridge Developmental Center resident is fighting to stay in her home
5. **New Jersey:** Families Of Developmental Center Residents Build Support At Grassroots Level
6. **Wisconsin:** For churchgoers with special needs, a special service takes some of the stress out

Special Feature

7. 'Autistic and Aging Out' Film

Calendar Reminders

Coming Up: 'Autistic and Aging Out' Film

VOR and You

1. VOR's Julie Huso to Address Wvominga

**Celebrating
Home: Holiday
Shop and
Benefit VOR**

About VOR

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

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

Families

VOR Press Release * October 28, 2013

Julie Huso, Executive Director of VOR, a national non-profit, non-provider, advocacy organization for people with intellectual and developmental disabilities (I/DD), will travel to Lander next week to tour the Wyoming Life Resource Center (WLRC) and meeting residents' families. She will meet with WLRC families on Monday, November 4, following the center tour, at the Lander Public Library, Carnegie Room.

"I'm excited to tour WLRC and meet the residents served so well there," said Huso. "With the help of our State Coordinator, Connie Howard, whose son receives WLRC services, VOR has been a present help in need for families, offering advocacy resources to show elected officials that WLRC is a quality, cost-effective home to residents."

[Read more](#)

2. VOR Submits Testimony In Response to California's Proposed Secured Perimeter Regulations

October 25, 2013

California is proposing to make permanent existing emergency regulations relating to 15 person home and community-based services (HCBS) waiver and Intermediate Care Facility homes with delayed egresses and secured perimeters for difficult-to-serve individuals with developmental disabilities. VOR's testimony raises questions with regard to the adequacy of minimum staffing criteria for resident safety, questions whether these residences will promote the hoped for integration in any real and meaningful way (in contrast to the expansive campuses of existing public ICFs/IID), and raises the question of whether these homes will be eligible for HCBS funding based on current federal policy and proposed regulation which, if finalized, would redefine

Reminders: Help VOR Grow!

Celebrating
Home: Holiday
Shop and
Benefit VOR

About VOR

Make a Lasting
Impact with a
Will Bequest

VOR.net:
Your one-stop
advocacy
resource

"community" for purposes of HCBS coverage.

[Read VOR's testimony](#)

Related:

* [Testimony of Kathleen Miller, President of the Parent Hospital Association of Sonoma Developmental Center](#)

* [Testimony of the California Association of Psychiatric Technicians](#)

3. VOR in the states: A recap

VOR has been busy advocating at the state-level, even as we continue to responding to federal issues, including the [Long Term Care Commission](#), the [National Council on Disability](#), the [Centers for Medicare and Medicaid Services](#), and [Congress](#). At the state level, in just the last month, we have submitted testimony in [California](#) and [Oklahoma](#), and have spoken to families in [Illinois](#) and [Arizona](#), and next week in [Wyoming](#).

VOR Members and Subscribers of this Weekly E-News Update are kept informed about VOR's advocacy efforts in support of residential and employment choice, and receive opportunities through [Action Alerts](#) to speak out directly to elected officials and federal policymakers.

If you know of someone who might like to benefit from receiving this publication, and an email version of our print newsletter, *The Voice*, VOR is now offering complimentary e-subscriptions to its publications in celebration of VOR's 30 years of advocacy. This complimentary subscription provides electronic access to VOR's publications until June, 2015. To activate a complimentary subscription(s), email jhuso@vor.net, reference "Complimentary Subscription," and provide names and email addresses. This information will never be shared or sold.

State News

4. Wisconsin: For churchgoers with special needs, a special service takes some of the stress out

The Star Tribune (Ashwaubenon, WI) * October 28, 2013

An evening service at Bethany United Methodist Church is casual enough that a visitor feels comfortable wandering to the front of the chapel to ask a question of the pastor halfway through.

The monthly family gathering steers away from the format of many church services, where congregants line up in pews quietly and might glance sideways at attendees who make noise or move around. This service was created for people who have autism or other sensory needs that may make sitting through a regular worship hour uncomfortable. The casual hands-on approach of the Bethany service also attracts families with young children.

A typical service includes moving to the front of the room to sing songs and say a prayer, followed by an interactive lesson. The October lesson was about superheros of the Bible, and participants stopped at various workstations in the church to decorate their capes and masks. Participants could say prayers for people in the aisles on the sides of the church.

[Read more](#)

5. New Jersey: Woodbridge Developmental Center resident is fighting to stay in her home

MyCentralJersey.com (Woodbridge, NJ) * [Article and Video](#) * October 9, 2013

Wendy English has a voice, and she's determined to use it to deliver a simple message.

"I want to stav here." said English. 50. a

resident of the Woodbridge Developmental Center on Rahway Avenue in the Avenel section of the township, one of two state facilities for the developmentally disabled the state is looking to close.

"I can't understand why they want to close WDC," said English, who is unsure where she will move, another developmental center or a group home.

"I have a life now at the WDC," she said with the aid of a computerized board containing prerecorded messages developed at the center. The board also displays the letters in the alphabet so she can point to spell out words.

English, who serves as her own guardian and will make her own decision about where she will live as the center closes, wants to know what options she would have if she is unable to thrive in a group-home setting. She says no one knows if there is a group home to meet her needs. If officials thought she could thrive in a group home, why was she brought to the developmental center 17 years ago, English points out.

She has signed a letter indicating her wish to remain at the Woodbridge Developmental Center.

[Read more, comment and share](#)

6. Families Of Developmental Center Residents Build Support At Grassroots Level

NJSpotlight * October 30, 2013

Summary: Advocates aim to sway Christie with local support and billboards, while also pursuing lawsuit

Families fighting to stop the closure of two state developmental centers are trying to build grassroots backing in municipalities as part of their effort to persuade Gov. Chris Christie and

**Celebrating
Home: Holiday
Shop and
Benefit VOR**

About VOR

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

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

legislators.

Save Residents' Homes at Developmental Centers, a coalition of center supporters, have gathered resolutions from 29 municipal governing bodies opposing the closure of centers in Woodbridge and Totowa.

A state task force decided to close the centers last year, leaving the state's densely populated northeastern corner without a large facility where people with developmental disabilities can live and receive a variety of services.

Family members have argued that closing the centers – two of seven in the state -- will disrupt the residents' lives and either make it more difficult for family visits to occur or expose residents to a lower level of care in small group homes.

Thirty-eight families of developmental center residents filed a lawsuit in June, alleging that the state violated the constitutional rights of the residents and broke a series of federal laws by deciding to close the facilities.

Joanne St. Amand, whose sister Rosemary Sciarillo has lived in the Woodbridge center for 38 years, has been visiting municipal councils since last year, trying to build local political support. The families also have been reaching out to their state legislators.

[Read more, comment and share](#)

Special Features

7. 'Autistic and Aging Out' Film

***Huffington Post* * October 2, 2013 * by Lauren Betesh**

"I got the great news," Andrew Roger said in a high squeaky voice, jumping up and down, tightening his fists then releasing them. He pulled his chair close to his computer and grabbed the mouse, clicking and scanning and reading the words of the Google search page

for "Seeds of Victory audio cassette tape." Then he stood back up, seized the TV remote and clicked on a Disney movie. He pressed rewind, fast forward, rewind again. Still holding the remote, he started to jump, pounding on his bedroom floor. "I got the great news!" Andrew said again.

But there was no news. Andrew, who's 18, has autism. Although he's verbal, his cognitive functions are severely impaired. When he does speak, his words are often indecipherable or repetitive, leaving him dependent on his parents for daily care.

I stood filming Andrew, but he was fixated on the television screen. At the time, I was unfamiliar with autism, knowing only that I was curious about the disorder and the impact it had on families. I knew they suffered a tremendous burden. I also knew that autism was rising in incidence. One in 50 children born today will be diagnosed with a form of the disorder, a staggering figure, according to a recent study by the Centers for Disease Control and Prevention and the Health Resources and Services Administration.

As I spent more time filming Andrew and Heidi (Andrew's mother) a clear problem emerged: Though formal programs for children diagnosed with autism continue through high school, at 21 these programs end, and the options for care become less clear. This process is known in the autistic community as "aging out."

What to do now? Heidi has multiple options -- placing Andrew in a group home, assisted living, a job, or having her son live at home until she becomes too old and weak to care for him. None, she explained, are a perfect solution.

[Read more, comment and share](#)

=====
[Calendar Reminders:](#)

March 25, 2014

AHCA/NCAL's ID/DD Residential Services Providers Hill Fly-In event. Questions? Contact Dana Halvorson, 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. [Details coming soon](#)

Week of June 9, 2013

VOR 2014 Congressional Initiative: Families and advocates visit Capitol Hill. [Details coming soon](#)

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.**

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.

