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April 10, 2015



Speaking out for people with
intellectual & developmental
disabilities



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**Reminders:
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VOR Weekly News Update

News and views for VOR Advocates

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VOR and YOU

1. [Registration](#) Open Through May 1, 2015 for VOR's Annual Conference
2. VOR Releases Groundbreaking Survey of Families of Adults with Developmental Disabilities; Dispels Myths, Shows Institutional Homes Are Part of Our Communities
3. VOR Submits Senate Testimony Opposing Federally-Financed Deinstitutionalization by U.S. Department of Health and Human Services Agencies.

STATE NEWS

4. **New York:** Can every person with a disability hold a regular job?
5. **Demand High For Specialized Housing**
6. **Home Care for people with disabilities : How direct care wages negatively affect quality of care**
7. **Montana:** Closing Montana Developmental Center would be fiscally irresponsible
8. **Virginia:** Failing Those Most in Need

**2015
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About VOR

QUOTABLE by Muhammad Ali

Calendar Reminders

COMING LATER TODAY: Your chance to submit testimony to the HOUSE Appropriations Subcommittee on Commerce, Justice, and Science regarding federally-financed DOJ deinstitutionalization actions.

VOR and YOU

1. Registration Open Through May 1, 2015 for VOR's Annual Conference

[Full Conference, Registration, and Hotel details are available on VOR's website.](#)

Thanks to the many of you who have already registered. We look forward to seeing everyone in Washington, D.C. this June.

2. VOR Releases Groundbreaking Survey of Families of Adults with Developmental Disabilities; Dispels Myths, Shows Institutional Homes Are Part of Our Communities

***PRNewswire* * April 7, 2015**

CHICAGO, April 7, 2015 /PRNewswire-USNewswire/ -- VOR, a national nonprofit organization that advocates for individuals with intellectual and developmental disabilities, including autism, has released the results of its survey of families of individuals with profound disabilities.

Believed to be the first of its kind, the "Giving a Voice to Families and Guardians" survey gathered the perspectives of families of individuals with profound disabilities who receive care in Medicaid Intermediate Care Facilities (ICFs) or in home and community-based settings. About three-quarters of respondents for both settings were parents and guardians.

"There is the assumption that all people with disabilities are better served in small settings, an assumption supported by other surveys," said Jill Barker, a VOR Officer and Board Member who chairs the committee who undertook the survey. "Yet, the opinions of the families who know best are rarely sought."

The 1999 U.S. Supreme Court's *Olmstead* decision ushered in a new decade of aggressive "deinstitutionalization," the movement of individuals with developmental disabilities from facility-based settings to smaller homes. This trend continues in states, with pressure from the federal government.

Olmstead, however, does not mandate deinstitutionalization, says VOR.

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PLEASE SHARE PRESS RELEASE WITH YOUR LOCAL MEDIA ([PDF](#), [Word](#))

The complete survey has been provided to VOR members. Nonmembers can receive a complimentary copy by joining VOR. [Click here for details.](#)

3. VOR Submits Senate Testimony Opposing Federally-Financed Deinstitutionalization by U.S. Department of Health and Human Services Agencies.

VOR * April 3, 2015 * Testimony submitted to the U.S. Senate Appropriations Subcommittee on U.S. Department of Health and Human Services

VOR strongly believe such forced deinstitutionalization activities are contrary to federal law and cause human harm. These deinstitutionalization activities, including advocacy, lobbying, class action lawsuits, and other tactics by some HHS-funded agencies that result in the downsizing and closure of HHS-licensed ICF/IID homes, some specialized group homes, sheltered workshops and day programs. These HHS v. HHS deinstitutionalization activities are a cruel and absurd use of federal funding.

Tragedies are widespread and predictable when fragile citizens are removed from specialized care. The legally-protected rights of families and legal guardians to serve as primary decision-makers are routinely ignored. Bill language prohibiting the very actions that lead to human harm and are contrary to federal law is desperately needed.

[Read complete testimony](#)

THANKS TO THE MANY VOR MEMBERS AND ADVOCATES WHO ALSO SUBMITTED TESTIMONY.

Coming up: Opportunity to submit written testimony to the U.S. HOUSE Appropriations Subcommittees on [Commerce, Justice, and Science](#) (due April 14) and [Labor, Health and Human Services, and Education](#) (due April 29). Alerts will be sent shortly.

STATE NEWS

4. New York: Can every person with a disability hold a regular job?

North Country Public Radio (Watertown, NY) * March 30, 2015

Under pressure from the federal government, New York is phasing out sheltered workshops. There is debate, however, in the disabilities community about whether closing the workshops

is a good idea. One sheltered workshop in Watertown, N.Y., is fighting to stay open.

[Read more, comment and share](#)

5. California: Demand High For Specialized Housing

Disability Scoop * April 6, 2015

The sound of hammers and saws coming soon to a vacant Reseda, Calif. lot means that someone like Stephanie Sullivan will have a home where she will be cared for and her needs understood.

Come January, Sullivan, who has Down syndrome, will move into the new home built by New Horizons, a San Fernando Valley nonprofit that helps those with developmental disabilities learn life skills, find employment and receive housing.

Sullivan will live there with five other residents such as herself, who are all facing their senior years with early onset Alzheimer's disease.

It is a rising but unanticipated trend for a population who once lived only until their 30s. The reality is a concern for both parents of older children with intellectual disabilities and those who run specialized programs and services for them.

[Read more, comment and share](#)

6. Home Care for people with disabilities : How direct care wages negatively affect quality of care

The DD News Blog * March 25, 2015 (by Jill Barker, VOR Officer and Board Member)

PHI (Paraprofessional Healthcare Institute) issued a [report](#) in February 2015 showing how the home care workforce is negatively affected by poverty-level wages, thereby degrading the quality of care for millions of elders and people with disabilities.

This is an especially timely topic with the federal government and federally-funded advocacy groups for people with developmental disabilities aggressively pressuring states to close institutions and other types of congregate care and services, often against the wishes of the people receiving this care and their families. The new rule for Home and Community Based Services ([HCBS](#)) from CMS [Centers for Medicare & Medicaid Services], the federal agency that regulates Medicaid and Medicare, as it is currently written, will inevitably lead to people with DD moving to less regulated settings, cared for by workers who are paid less with fewer benefits or other incentives to remain in their jobs.

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7. Closing Montana Developmental Center would be fiscally irresponsible

***Independent Record (Helena, MT) * Opinion Editorial by
Lowell Bartels * April 8, 2015***

For nearly 40 years, I have witnessed the changes at the Montana Developmental Center from a hospital/dormitory-like institution where the disabled were isolated from communities to its closure when the developmentally disabled were moved into communities. Those who had difficulty living in communities were sent to prison. Then, the state reopened the MDC as a collection of group homes and rehabilitation workshops that prepare individuals to re-enter communities.

For more than six of the past 25 years, I have volunteered as a chaplain at MDC and have visited the campus on a weekly basis. Because of this connection, I am personally acquainted with many of the clients and staff members. I can speak as a person who has no financial interest in the outcome of Senate Bill 411.

The MDC is staffed by many sincere, hard-working people who are dedicated to helping some of Montana's most difficult developmentally disabled clients.

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8. Virginia: Failing Those Most in Need

**Connection (Oak Hill & Herndon) * April 9, 2015 Letter to the
Editor by Maureen Houser**

My name is Maurine Houser and I am writing in response to your article ["Moving: From Institution to Community"] printed on April 2 regarding the Northern Virginia Training Center.

I am the younger sister and guardian of my 57-year-old brother Kim Houser. Until recently, he resided at the Northern Virginia Training Center. Kim is non-verbal, non-ambulatory without assistance, has the cognitive ability of a nine month old and is medically fragile.

Your article states that the state Department of Behavioral Health and Developmental Services has provided a multitude of community placement options for family members.

However, it has been my experience and others that the placements offered are inappropriate and do not have the skills or supports necessary for the medically disabled and behaviorally challenged population remaining at the Northern Virginia Training Center to survive.

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QUOTABLE

*"The man who views the world at 50 the same as he did at 20
has wasted 30 years of his life." ~ Muhammad Ali*

Calendar Reminders:

Sunday, June 7, 2015:

**[VOR Annual Conference: ADVOCATING FOR
CHOICE BY EXPANDING OPPORTUNITIES. Registration
Open.](#)**

Archives:

* **Thursday, March 20, 2014**

[VOR's "Regional Meetings: The Need for Advocates to Act
Global and Local" Webinar.](#)

***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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