



Speaking out for people with intellectual & developmental disabilities



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News and views for VOR Advocates

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VOR and YOU

1. Press Release: VOR, National Disability Advocate Visits Misericordia, Premier Caregiver for People with Developmental Disabilities

VOR * August 25, 2014

CHICAGO - Julie Huso, Executive Director of VOR, a national, nonprofit organization advocating for high quality care and human rights for people with intellectual and developmental disabilities, traveled to the Chicago-area to meet with representatives of [Misericordia](#).

Located in Chicago, Misericordia is home to more than 600 children and adults with intellectual and developmental disabilities, offering those in their care a community of support and opportunities.

“Misericordia is home, in every sense of that word, to the individuals who live there,” Huso said. “It is a special place.”

[Read more, comment and share](#)

2. VOR’s Wyoming Co-State Coordinator, Shawn Humberson, Makes Public Plea to Family Advocates in Open Letter: Fragmented, we are iust whispers. United. we are a chorus.

About VOR

Make a Lasting
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About VOR

***The Lander Journal* * August 20, 2014**

My name is Shawn Humberson. I am a State Co-Coordinator for VOR and a Friends of Wyoming Life Resource Center (WLRC) Board member. My profoundly disabled aunt has lived at the WLRC for the past seven years after spending the first 34 years of her life at home and receiving services from community programs. She was one of the first enrolled in the Medicaid Waiver Program. I am one of her co-guardians. I also work as a home trainer in a community program.

As you can see, I am deeply, personally and professionally, vested in Wyoming's intellectually and developmentally disabled (I/DD) population. From my perspective, our current and future DD population is at risk. The Wyoming Department of Health (WDH) is making critical changes across the board. These changes are in response to state legislation and new federal regulations. These changes are not necessarily in the best interests of the Developmentally Disabled.

[Read more, comment and share](#)

3. VOR Board Member, Mary Reese's Letter to the Editor: Holly Center Cottage Closure Chilling

***The Daily Times (Salisbury, Maryland)* * August 25, 2014**

The Holly Center administration recently announced the closure of another of its residential cottages. After this closure, there will only be 4 of the original 9 cottages in service; the current census is well under half of its original capacity. Holly Center is a federally regulated facility operated by the state of Maryland to serve those with intellectual and / or developmental disabilities (IDD).

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I am the legal guardian of a 70 year old woman, Ginger, with profound IDD who requires 24/7 total care and is medically fragile. Ginger has lived in a facility based setting and in a group home setting; we have experienced both. The group home, or community residential program, was inadequate to meet her complex needs. The state only allowed Ginger's admission to Holly Center after she suffered serious injury at the result of the group home staffs' neglect.

[Read more and share](#)

4. VOR's Kansas State Coordinator, Joan Kelly, Delivers Testimony Before KanCare Oversight Committee

August 12, 2014

**Testimony on KanCare Oversight: Challenges and Outcomes for our Most Vulnerable Before the Robert G. (Bob) Bethell Joint Committee On Home And Community Based Services And Kancare Oversight
Delivered by Joan Kelly, Stakeholder and Legal Guardian
[Vice President, Kansas Neurological Parent Group; VOR Kansas State Coordinator]**

Good afternoon, Chairman David Crum and members of the Committee,

Thank you for the opportunity to give presentation today, and I want to commend this Committee for your ongoing work and service.

As a stakeholders who believe in community, my husband and I utilized an array of community based services for our profoundly disabled grandson in the State of Kansas beginning 1998.

Our loved one currently lives at KNI, the Kansas Neurological Institute, residing there since the fall of 2008. He was placed there after exhausting every community option, and although we have sought reintegration. our search continues. as

unfortunately, a number of community providers have refused to serve him.

[Read more, relating to “Systemic Deficiencies” in the areas of quality of care, abuse and costs.](#)

5. VOR Member, Linda Scherer’s Letter to the Editor: Developmentally disabled need Holly Center as choice

The Daily Times (Salisbury, MD) * August 28, 2014

With news of some changes at Holly Center, I am writing as a family member of a Holly Center resident who is happy in his home, thrives there and receives many services and relationships enhancing his health, well-being and independence.

My brother is 58, has multiple disabilities and has been a resident since 1976, when our parents (now deceased) moved to Salisbury specifically to help assure my brother's placement at Holly Center, which was and continues to be a top-notch home for him.

[Read more and share](#)

STATE NEWS

6. California: Parent Praises Sonoma Developmental Center Staff and Parent Hospital Association (PHA) Efforts on Behalf of SDC Residents

To the Sonoma Developmental Center and the Parent Hospital Association:

As some of you know, my daughter Ana Cuadrado, was a client at Sonoma Development Center and after a recent battle, she passed away peacefully last month. During my healing process, I want to thank you for giving me the opportunity to write a letter to all of you.

In this letter, I want to share my sincere and heartfelt gratitude towards the immensely dedicated people that were Ana's "SDC family" over the past five years. You all were an incredible force for Ana, myself and our family; and words cannot express how much our family appreciates your support and services.

[Read more, comment and share](#)

7. South Dakota honors frontline workers who support people with disabilities

**South Dakota Department of Human Services *
August 21, 2014**

PIERRE, S.D. – Gov. Dennis Daugaard is recognizing the important efforts of those who work closely with people with intellectual and developmental disabilities by proclaiming Sept. 7-13 as Direct Support Professionals Recognition Week in South Dakota.

Direct support professionals (DSPs) are the primary providers of publicly funded long-term supports and services for individuals with disabilities. They work at the 19 Community Support Provider agencies throughout the state as well as at the South Dakota Developmental Center in Redfield.

Thousands of South Dakotans with disabilities are able to live and work as independently as possible because of the essential supports provided by DSPs. They also help keep individuals with disabilities connected to their families, friends and communities.

"Direct support professionals form the backbone of South Dakota's community supports and services," said South Dakota Department of Human Services Secretary Gloria Pearson. "It's important for South Dakota to be able to recruit, train and retain a highly qualified DSP workforce and to recognize the skilled and compassionate support

they provide.”

Various programs, activities and ceremonies will take place across South Dakota Sept. 7-13 during Direct Support Professionals Recognition Week to honor the state’s long-term supports and services workforce. U.S. Senate Resolution 532 has also established the week beginning Sept. 7 as National Direct Support Professional Recognition Week to celebrate DSPs across the country.

[Read the Proclamation](#)

AUTISM NEWS

8. Study Offers Clues To How Autism Develops

***Disability Scoop* * August 22, 2014**

Kids with autism retain extra brain connections that other children weed out during development, researchers say in a new study that suggests drugs may be able to correct the issue.

The connections, known as synapses, allow neurons in the brain to communicate with each other. Typically, as children grow, they go through a pruning process to limit the number of synapses.

However, that does not appear to occur properly in children with autism, leaving such youngsters with too many synapses which can affect how the brain functions, according to [findings](#) published Thursday in the journal *Neuron*.

[Read more, comment and share](#)

9. Support Growing For Autism Behavior Therapy

***Disability Scoop* * August 22, 2014**

A new government-backed review finds that there

is substantially more evidence for behavior therapy in treating autism than even just a few years ago.

[Read more, comment and share](#)

HEALTH CARE RESEARCH

10. Doctors Get New Recommendations For Diagnosing Disabilities

***Disability Scoop* * August 25, 2014**

A major pediatricians' group is issuing new guidelines for physicians diagnosing intellectual and other developmental disabilities.

In a clinical [report](#) published Monday in the journal Pediatrics, the American Academy of Pediatrics updated its recommendations, which were first released in 2006.

Specifically, the new report emphasizes advances in genetic testing in recent years that can aid in providing a more precise diagnosis for children with various delays.

It is important to identify the root of a child's disability, when possible, to provide the most appropriate treatment plan, the report said. What's more, identifying a precise diagnosis can help families manage expectations, advocate for their child and obtain services and supports, they indicated.

Beyond diagnosing children, the recommendations also emphasize the responsibility doctors have to help connect families with special education and developmental services.

[Read more, comment and share](#)

11. People With Down Syndrome Are Pioneers In Alzheimer's Research

***NPR Mornina Edition* * August 25, 2014**

When researchers at the University of California, San Diego wanted to [study](#) an experimental Alzheimer's drug last year, they sought help from an unlikely group: people with Down syndrome.

Alzheimer's researchers are increasingly interested in people like McCowan because "people with Down syndrome represent the world's largest population of individuals predisposed to getting Alzheimer's disease," says Michael Rafii, director of the Memory Disorders Clinic at UCSD.

Down syndrome is a genetic disorder that's best known for causing intellectual disability. But it also causes Alzheimer's. "By the age of 40, 100 percent of all individuals with Down syndrome have the pathology of Alzheimer's in their brain," Rafii says.

[Read more, comment and share](#)
[Listen to the NPR Morning Edition story](#)

QUOTABLE

"Fragmented, we are just whispers. United, we are a chorus." ~ Shawn Humberson, VOR Wyoming Co-State Coordinator

Calendar Reminders:

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 information and the schedule can be found [here](#).

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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