

September 5, 2014



Speaking out for people with intellectual & developmental disabilities



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**About VOR**

## VOR Weekly News Update

*News and views for VOR Advocates*

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**Make a Lasting  
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**VOR and YOU**

**1. VOR's Georgia Affiliate Submits  
Comments in Response to State's Remedial  
Plan**

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**VOR \* August 25, 2014**

In March 2014, the Independent Reviewer overseeing the Settlement Agreement in U.S. v. Georgia cited State non-compliance in areas affecting the health and well-being of affected citizens with intellectual and developmental disabilities ([tragedies that were also reported in the press](#)). In addition to ordering a continued moratorium on the transitions of individuals with I/DD from State Hospitals (Medicaid licensed Intermediate Care Facilities for Individuals with Intellectual Disabilities), the Independent Reviewer required that the State write a plan by June 30, 2014 that is designed to bring the State's support coordination system into compliance.

The VOR Georgia affiliate, East Central Regional Hospital Family Council, with VOR's support, recently offered its comments in response to this "Priority Plan."

[Read the Family Council/VOR comments here.](#)

**2. Press Release: Julie Huso, VOR's  
Executive Director, represents VOR at South  
Dakota Developmental Center Annual  
Celebration**

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**VOR \* September 3, 2014 \* For Immediate Release**

## About VOR

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## About VOR

REDFIELD - Julie Huso, Executive Director of VOR, a national organization for people with intellectual and developmental disabilities, will attend the South Dakota Developmental Center's annual Fall Festival celebration later this week in Redfield, South Dakota.

Huso, who has served as VOR's Executive Director for more than five years and has worked as a disability advocate for more than 25 years, will speak with families and staff about national issues impacting the lives of those with intellectual and developmental disabilities and their families, and spend the day enjoying the celebration.

"The South Dakota Developmental Center such a well-run and a beautiful home for its residents. It is a gem that South Dakota citizens should be very proud of," said Huso. "South Dakota's support for the center is a bright spot so unlike the service and funding challenges facing many individuals with intellectual and developmental disabilities across the country."

[Read full release here](#)

### **HOME AND COMMUNITY BASED SERVICES RULE AND EMPLOYMENT**

#### **3. Free Webinar: Community-Based Settings and the New Medicaid HCBS Standards: View from States, 6 Months In**

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National Senior Citizens Law Center

September 9, 2014, 2-3 pm eastern.

Click here to register: [Community-Based  
Settings and the New Medicaid; HCBS  
Standards: Views from the States, 6 Months In](#)

#### **4. New federal rules could close sheltered workshops for people with disabilities**

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**Make a Lasting  
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***Kansas City Star \* August 25, 2014***

The future of such places — sheltered workshops that pay subminimum wage to workers with various disabilities — is uncertain in light of a [new Medicaid rule](#) and a new law, the [Workforce Innovation and Opportunity Act](#), signed last month. Based on a 1999 Supreme Court decision, the two actions confirm the government’s commitment to integrate people with disabilities into the larger community as much as possible.

But the Missouri Association of Sheltered Workshop Managers says “workshop veterans and their family members realize that placing all workshop employees in private, competitive businesses is unrealistic.”

Not everyone with a disability can hold down a job in the open market.

“If people were able to have community employment, they would be community employed,” said Barb Winkler. “It’s a little disturbing that we build programs for people with developmental disabilities and then we come along and dismantle them and try something else for a while.”

[Read more, comment and share](#)

**LEGAL BRIEFS**

**5. New Mexico: Lawsuit argues Medicaid Supports Intensity Scale (SIS) evaluations hurt disabled**

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***Associated Press \* August 24, 2014***

ALBUQUERQUE, N.M. — Family members of developmentally disabled New Mexicans suing the state say a Medicaid-assessment system, the Supports Intensity Scale (SIS), puts recipients of services at risk, the [Albuquerque Journal](#) reported.

Attorneys for eight families asked a judge Wednesday to halt a new method for evaluating recipients to determine their level of services, which can include 24-hour residential care as well as occupational and speech therapy.

In the lawsuit, plaintiffs state that 700 recipients have challenged the accuracy of their assessments and categories of care they were assigned. The new evaluation system uses "vague, subjective and arbitrary criteria and procedures," the lawsuit said, and violates the due-process rights of recipients.

Once a recipient is assigned care based on his or her evaluation score, "they are tied to a limited base budget and menu of available services without regard to individual medical need," the lawsuit said.

However, the governor's office disputes that claim and said the changes such as the evaluation system, the Supports Intensity Scale, were to help people off waiting lists for services.

[Read more, comment and share](#)

## **6. Illinois: Judge Aspen Has Ruled - Now What?**

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**Murray Family Association \* August 2014**

In a [ruling](#) on July 21, 2014, District Judge Marvin E. Aspen denied our plaintiffs' motion for a preliminary injunction in which the plaintiffs, the Illinois League of Advocates for the Developmentally Disabled (IL-ADD), the Murray Parents Association (MPA) and certain individual plaintiffs sought to stop the process by which the state was going about the closure of Murray Developmental Center.

In our complaint, we, the plaintiffs, maintained that the state was not following federal law in the closure process, including not respecting guardian choice in the placement decision. Our first step was to seek a preliminary injunction to stop that process until the state was in

compliance with federal law.

Relying upon the state's sworn testimony that it was following the law, the judge denied our plaintiffs' motion for a preliminary injunction and declared that the closure process at Murray may continue. But at the same time, the judge categorically affirmed certain vital rights of residents and guardians regarding the process of assessment and the choice of placement.

Judge Aspen's reliance on the state's sworn testimony that choice will be honored and that all choices are available up to and including SODCs is an affirmation of the right of guardians to choose.

[Read more and share](#)

[Read Related Press Release by the Illinois Association of Intermediate Care Facilities for Individuals with Developmental Disabilities \(ICF/DD\) Providers \(IAIP\)](#)

**Editor's Note:** *Despite the favorable aspects of Judge Aspen's ruling, the Plaintiffs still appealed his decision to deny their request for a preliminary injunction, arguing that the plaintiffs remain at risk of irreparable and grievous harm as a result of loss of their required service and the guardians' right to a clear choice encompassing all available options." Although the Defendants (the State) have made promises to honor individual and guardian choice, the State's "plan and operation of the plan recategorized and recast Plaintiffs' severity of disability," thereby forcing them to accept in adequate services so that funds used for their services could be used to provide services for less severely developmentally disabled persons, amounting to "intra-disability discrimination." The article that follows is a very good overview of the plaintiffs' appeal.*

**7. Wisconsin: Legal brief challenges**

## Wisconsin hospital's "end-of-life" practices

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*Galaxy Report* \* June 3, 2014

Fourteen disability rights groups filed an *amicus* brief May 23 in a four-year-old case challenging the University of Wisconsin Hospital Center's alleged "practice of counseling families of people with developmental disabilities to withhold care for treatable but potentially life-threatening medical conditions."

"We need the court to recognize that people with disabilities shouldn't be refused care simply because a doctor doesn't think their lives are worth living," said Samantha Crane, director of public policy for the Autistic Self Advocacy Network, in a news release. "Often, this sort of judgment serves as cover for discriminatory denials of care."

The case centers on two incidents at the hospital. In the first case, the director of hospital's ethics committee allegedly told a hospital physician in August 2006 that he should withdraw antibiotics, nutrition and hydration from a 13-year-old boy, despite his history of responding well to the treatments.

Months later, the boy died of pneumonia. As the disability advocacy groups see it, the "only apparent justification for this course of action was the fact that the boy had a significant developmental disability and therefore was perceived to have a 'low quality of life.'"

In another case, a doctor at the hospital allegedly counseled the family members of an adult woman with developmental disabilities to withdraw her from certain antibiotics that were being used to treat an acute respiratory infection.

Disability Rights Wisconsin filed a lawsuit in 2009, accusing the hospital of violating the Wisconsin and U.S. Constitutions by failing to

providing life-saving treatments to these individuals. The Dane County Circuit Court dismissed the complaint in December 2013, prompting the current appeal.

In the *amicus* brief, filed in the Wisconsin Court of Appeals District IV, the advocacy groups argued that state law limits the authority of family members and guardians to decide whether to withdraw life-saving medical treatments. In addition, they argued that hospitals and hospital physicians have a corresponding duty to provide lifesaving care.

“People with disabilities are at particular risk of being deprived of medical care if state-employed physicians are granted immunity for their participation in plans to end life through withdrawal of lifesaving care,” the *amicus* brief states. “Amici therefore urge the Court of Appeals to recognize state-employed physicians’ legal duty to avoid abetting courses of action that, under Wisconsin law, constitute homicide through deprivation of care.”

In addition to the Autistic Self Advocacy Network, Not Dead Yet, ADAPT, American Association of People with Disabilities, American Council of the Blind, Association for Autistic Community, Association of Programs for Rural Independent Living, Autism Women’s Network, National Association of the Deaf, National Council on Independent Living, National Disability Rights Network, Quality Trust for Individuals With Disabilities, United Spinal Association and the Wisconsin Board for People With Developmental Disabilities joined the *amicus* brief.

[Read, comment and share](#)

## **STATE NEWS**

**8. New Jersey: State hears concerns over developmental center closure**

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**MyCentralJersey \* September 5, 2014**

NEW BRUNSWICK – Jackie Guillot dreamed of buying a house near the state developmental center where her brother George lived so she could have him over for dinner on Sunday afternoons.

“My dreams were shattered,” said Guillot, 52, adding her brother, 58, who lived at the Woodbridge Developmental Center for 37 years was recently moved to a developmental center in South Jersey as the state prepares to close the Woodbridge facility by the end of the year. North Jersey Developmental Center was closed earlier this summer.

Guillot, a local resident, who has lupus, said the distance to the Woodbine Developmental Center is too far for her to regularly travel to visit her brother.

[Read more, comment and share](#)

## **QUALITY IN THE COMMUNITY**

### **9. In-Home Caregivers Often Lack Training, Oversight**

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**Disability Scoop \* August 29, 2014**

Each day, thousands of home-based caregivers are thrust into life-and-death situations with little training and virtually no direct supervision. They perform a dizzying array of complex medical tasks — from inserting feeding tubes and cleaning infections to monitoring intravenous fluids — that once were provided only in hospitals or nursing homes by medical professionals.

Many say they feel overwhelmed and unqualified as they struggle to help patients with serious illnesses and disabilities.

In Minnesota, where more than 100,000 care

assistants serve some 36,000 vulnerable patients, all it takes to be certified as a home caregiver is a brief online quiz with questions such as, “When talking to a 911 operator, do not hang up. True or false?”

Of more than two dozen personal care attendants interviewed by the *Minneapolis Star Tribune* in the past two months, only one had received more than an hour’s training from their agencies. Many said they appealed to their agencies for more training and oversight but were told that state payments were too low to cover the expense.

The same pattern plays out across the country. Despite a decade of explosive growth in the \$95 billion home-health industry, which is swelling to meet the demands of an aging population, there are no federal standards for the training, credentials and supervision of personal care attendants.

The type of work demanded of home caregivers has changed dramatically in the past two decades.

Hospitals, under pressure from insurance companies to reduce costs, are releasing more patients while they are still sick or recovering, effectively shifting the burden of medical care to the home. Caregivers have had to master the operation of respiratory ventilators, intravenous feeding tubes and home dialysis, while responding to medical complications such as wound infections and low oxygen levels.

More than 80 percent of home caregivers provide nursing care, while more than 50 percent provide help with highly complex medical tasks, according to a survey of 1,926 home care workers who cared for adult Medicaid recipients in three states.

[Read more, comment and share](#)

## QUOTABLE

*"Faith is taking the first step, even when you don't see the whole staircase."* ~ Martin Luther King, Jr.

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### **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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