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October 4, 2013



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disabilities



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VOR Weekly News Update

News and views for VOR Advocates

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VOR and You

1. VOR's Executive Director Brings VOR's Residential Choice Message to Individuals, Families and Providers in Illinois and Arizona

VOR * October 4, 2013 * For Immediate Release

Julie Huso, VOR's Executive Director, traveled to the Chicago-area last week to meet with individuals with I/DD and their families. During her week-long visit, Huso toured public and private facilities for people with I/DD, shared information about VOR's national advocacy with families of disabled individuals, and met with VOR leaders and members.

[Read Complete Press Release here](#)

This weekend, she will travel to Arizona to represent VOR at the American Health Care Association/National Center for Assisted Living's ID/DD Day in Phoenix, Arizona. The AHCA/NCAL conference includes education sessions, inspiring general sessions, and an interactive Expo Hall for long-term and post-

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acute care professionals for seniors and people with disabilities. While in Arizona, Julie will also visit the Arizona Training Center (ATC) in Coolidge, a state-operated long-term care facility for people with I/DD. As a Medicaid-licensed facility, ATC provides individualized treatment services and supports to people with developmental disabilities and challenging behaviors when needed services are not available in a community setting.

[Read Complete Press Release here](#)

2. Book Review: The Story of a Remarkable Woman. VOR's George Mavridis publishes memoir of his inspiration for his life-long advocacy – his cousin, Joanna.

**Real Choices in Care Blog * September 10, 2013 *
by David Kassel**

Editor's note: George Mavridis is a long-time VOR member, State Coordinator and Legislative Committee member. He has attended VOR's Annual Conference and Washington Initiative for the past decade, often carrying with him a letter "from" Joanna – written by George in Joanna's voice to help Members of Congress and their staff to help them recognize that their work impacts real people with real needs. George's book – "Joanna, God's Special Child," is his thank you to his cousin for bringing out the brother, father and advocate in him for the past 45 years. A book review, written by David Kassel follows. The book is available on [Amazon](#).

The Story of a Remarkable Woman

I never met Joanna Bezubka, who lived at the Fernald Developmental Center for 39 years and then spent the final seven years of her life in a state-operated group home in Lynnfield, Massachusetts.

But after reading "Joanna, God's Special Child," a new memoir by George Mavridis, I feel I got to know her well enough that I'm sad I never will meet her in the flesh. That's because Mavridis, Joanna's cousin and co-guardian, has written an account of her life that makes you realize what a truly remarkable person she was — filled with charm and humor and an

independent spirit.

[Read Review](#)

[To order George's book, visit Amazon.com](#)

3. VOR joins other advocates in call to U.S. Health and Human Services Secretary, Kathleen Sebelius, to support individual choice and an inclusive definition of “community”

September 27, 2013

Sixteen state and national organizations, including VOR, sent a letter to Kathleen Sebelius, Secretary of the U.S. Department of Health and Human Services' (HHS), and Marilyn Tavenner, Acting Administrator for the Centers for Medicare & Medicaid Services (CMS), and a separate letter to James K. Haveman, Director of the Michigan Department of Community Health.

Coordinated by the [Madison House Autism Foundation](#), the signing groups called on Secretary Sebelius and Administrator Tavenner, and Director Haveman, to embrace principles in support of individual choice, as required by Olmstead, and to reject a definition of “community” which would prevent innovative housing options. The letter was in response to the Arc of Michigan, which asked these officials to halt funding for “congregate” options.

HHS/CMS is currently reviewing a proposed rule that, if finalized, would so narrowly define community that many current and future housing options for people with I/DD and autism would be denied Medicaid funding under its home and community based services programs. Groups joining the letter to Secretary Sebelius and Administrator Tavenner have been outspoken opponents of the proposed rule.

[Read the groups' letter to Sebelius and Tavenner](#)

[Read the groups' letter to Haveman](#)

[Read related blog by Jill Barker, VOR's First Vice President and Board Member \(Michigan\)](#)

State News

4. South Dakota: Developmental Center celebrates residents, staff, community with Fall Festival

**South Dakota Department of Human Services *
September 27, 2013**

Editor's note: VOR's Tamie Hopp attended this fun celebration. The Governor's visit was very much appreciated by residents, their families, and staff. Representatives from U.S. Senator John Thune (R-SD) and U.S. Representative Kristi Noem (R-SD) also attended; U.S. Senator Tim Johnson sent a supportive letter which was read.

Gov. Dennis Daugaard attended the South Dakota Developmental Center's Fall Festival on Friday, September 20, 2013 to present awards and spend time with residents, staff and community members in Redfield.

Before speaking about the significance of SDDC and its residents with developmental and intellectual disabilities, Daugaard took a moment to acknowledge a fall display that offered a humorous welcome for South Dakota's chief executive: a scarecrow dressed as a skydiver and attached to a mock parachute, hanging from a tree next to a sign that read "Thank you for dropping in on Fall Festival!" The Governor, recently parachuted from 10,000 feet as part of a fundraiser.

Dr. Ted Williams, director of SDDC and interim cabinet secretary of the state Department of Human Services, said the Fall Festival is a longstanding tradition that recognizes not only the importance of SDDC's residents and staff. but also acknowledges the

important relationship between the facility and the surrounding community.

Without the tremendous support we receive from the community, we would not be able to provide the quality supports for our residents that the state has come to expect from SDDC,” Williams said.

[Read more, comment and share](#)

5. Illinois: Attorney General Madigan Attempting to Remove Freeman as Murray Center State Ward Guardian

*WJBD News (Salem, IL) * October 2, 2013*

The decision of Attorney General Lisa Madigan to try and remove Attorney Stewart Freeman as guardian ad litem over the wards of the state at Murray Center is drawing fire.

So is the decision to use Equipped for Equality (Illinois’s P&A) to look into problems found at community homes (“CILAs”) in the Centralia area detailed by Freeman in an affidavit taken as part of the federal lawsuit to keep Murray Center open.

State Representative Charlie Meier says there will be a fight to keep Freeman as an overseer of the Office of State Guardian who he feels has not been doing its job to protect the wards of the state. The same day Freeman filed an affidavit critical of the care received by former Murray residents in community settings, the state filed to have him removed as Guardian Ad Litem.

[Editor’s Note: [Freeman was appointed by Judge Dennis Middendorff after Murray employees sought legal protection for Murray residents who had been “wards of the state” and represented by the Illinois Office of State Guardians \(OSG\)](#). Employees alleged that OSG was putting their wards at risk by transitioning them from Murray to unsafe placements without adequate attention or knowledge of individual

needs.]

Freeman outlined numerous problems during visits to several of the CILAs in Centralia and Mt. Vernon, including one case where a ward of the state did not received medication for three days resulting in a seizure and another incident where a resident requiring a feeding tube had the prescribed formula replaced with store bought Ensure when the formula ran out.

Meier finds it equally interesting the State Department of Human Services is turning to Equip for Equality for an investigation of the alleged problems.

"They're one of the groups who lined up to close Murray Center, and they're supposed to be our 'third party mediator. I find that rather funny, but that is what the state does: keep going to their friends to help them out" Meier said.

After reading Mr. Freeman's affidavit regarding his services as the Guardian Ad Litem and the treatment these OSG wards have had to endure, the President of the Murray Parents Association Rita Winkeler says she sincerely hopes that Judge Becker's order will stand. She feels someone has to defend the rights of these residents who do not have parents or guardians to do so, as it is obvious the state is not doing so.

Winkeler says they are also distressed that the state would say they are sending in Equipped for Equality to review the homes. She notes part of the state's filed documents in the federal lawsuit is a letter that Equipped for Equality wrote in favor of closing Murray Center. Winkler says they can hardly be called an unbiased entity when their goal is to close all state facilities. She hopes the Judges in the appeal case will realize that the safety of these residents depend on someone like Mr. Freeman who is more concerned about the life and safetv

of these residents, than he is about closing the doors of Murray Center.

[Read more, comment and share](#)

6. Maryland: State owes \$21 million for faulty Medicaid claims, report says

***The Baltimore Sun* * September 13, 2013**

A federal investigator has found that Maryland's Medicaid program had a 95 percent error rate in seeking reimbursement for room and board for the developmentally disabled and thus owes the U.S. government nearly \$21 million.

Advocates expressed concern that the findings could lead to budget cuts to the program and longer stays on waiting lists for vulnerable individuals and struggling families.

In a report released Friday, the inspector general for the U.S. Department of Health and Human Services said that over a three-year period, state health officials routinely billed the federal government for room-and-board costs that were ineligible under Medicaid rules. Medicaid is a joint federal-state program to pay for health care for the poor and disabled.

In more than half of the cases tested between July 2009 and June 2012, the investigation determined that Maryland reduced the claims made by private providers of services to disabled people but failed to pass on those reductions to the federal government.

"The state agency claimed these unallowable costs because it lacked internal controls to ensure that unallowable costs were not included in claims for provider per diem payments," the inspector general wrote.

In its reply, the state health department said it agreed with the federal findings and has taken steps to correct the errors. In a letter to Inspector General Stephen Virbitskv. Health

Secretary Joshua M. Sharfstein promised that his department would "actively monitor and review" the steps it has taken to prevent future errors in claims for federal reimbursement.

[Read more, comment and share](#)

7. Florida: Disabled Children Lose Class Cert. Bid In Suit Against State

***Law360* * September 25, 2013**

A Florida federal judge denied class certification Wednesday in a suit accusing health officials of putting disabled children at risk of institutionalization by denying them Medicaid services they are allegedly owed, deciding the suit might involve individualized claims of alleged discrimination.

U.S. District Judge Robin S. Rosenbaum found it isn't yet clear whether the plaintiffs are making allegations on a case-by-case basis (not appropriate for class action) or challenging Florida's policies (possible class action) on disabled children, which the U.S. government is also contending.

Judge Rosenbaum denied class certification, but she gave the plaintiffs 90 days to refile their motion and 75 days to conduct discovery related to class certification.

"Due to the parties' drastically diverging theories in this case, some discovery may be helpful in resolving the class certification issue," the Wednesday order said.

Judge Rosenbaum said the dispute can be handled as a class action if the plaintiffs sufficiently allege a systemic problem in the way Florida treats disabled children but perhaps not if it involves the individualized application of such policies "in a handful of cases."

"At this juncture ... the record is not sufficiently developed for the court to be able to discern what may be the case." the Wednesday

order said.

[Read more, comment and share](#)

Employment Choices

8. Sheltered workshops under fire in Massachusetts

COFAR Blog * September 30, 2013

Paul Buonomo enjoys his job stuffing envelopes, collating papers and carrying out other tasks in a program in Danvers known as a sheltered workshop.

His parents, Doris and Joe Buonomo, maintain that the workshop, run by Heritage Industries, is the best such program Paul has ever been in.

But in the wake of a national debate over the political correctness of sheltered workshop programs for people with developmental disabilities, programs such as Paul's may soon be phased out. Here in Massachusetts, the Department of Developmental Services is reviewing its policies regarding sheltered workshops and has invited state-funded providers into a working group to determine what the future will be for the programs.

Sheltered workshops provide opportunities for developmentally disabled people to do assembly work and other tasks, usually for a small amount of pay, in group settings. The charge of political incorrectness stems from the fact that the workers are not participating in the nation's mainstream workforce and are therefore allegedly being "segregated" from non-disabled people. In many – perhaps in most – cases they also receive sub-minimum wages.

The charge that sheltered workshops promote segregation and inadequate pay to disabled people is being leveled not only by a number of advocacy groups, but by government agencies.

including the federal Department of Justice and the National Council on Disability.

These are the same advocates and agencies, by the way, that have long opposed all forms of congregate care for the developmentally disabled.

But supporters of sheltered workshops, many of whom are family members of the workshop participants, argue that these programs provide their loved ones with fulfilling work and skill-building activities, and that if the programs were eliminated, there would often be nothing to take their place.

[Read more, comment and share](#)

10. New York: Office for Persons With Developmental Disabilities (OPWDD) holds Town Hall Meetings to Focus on People with Disabilities and Employment Options

OPWDD Community Dialogue Summary * September 27, 2013

The New York Office of Persons With Developmental Disabilities (OPWDD) held “town hall” Community Dialogues around the state to hear from stakeholders regarding the employment options for people with developmental disabilities.

In an OPWDD summary of stakeholder feedback from these sessions, many stakeholders raised concerns about proposals which would limit the range of employment options available to people with developmental disabilities. Stakeholders expressed concerns about federal expectations with regard to competitive employment, with several witnesses speaking to failed efforts and the value – monetarily, self-esteem, and training – of sheltered employment options. Concerns were also raised about the interpretation of the *Olmstead* Decision and whether it requires

workshops to be closed.

VOR member Linda Blumkin was among those testifying:

“For those who are not capable of working in community settings but are still capable of work, and want to work, and enjoy the company of their colleagues and the staff at a sheltered workshop, this can be a meaningful alternative – and one vastly superior to spending their days in less productive (or nonproductive) activities at their residences.” (Testimony of Linda Blumkin, VOR member, before a New York Office for Persons with Developmental Disabilities Town Hall Meeting (September 13, 2013).

Read more:

[OPWDD Summary of Stakeholder Feedback
Linda Blumkin’s Testimony](#)

11. Harkin and sheltered employment

***Press Release * U.S. Senator Tom Harkin *
September 26, 2013***

In a new report, Harkin calls for enactment of several key pieces of legislation—including a reauthorization of the Workforce Investment Act (WIA) — to create opportunities and incentives for young people with disabilities to work. The HELP Committee recently passed by a bipartisan vote of 18-3 a WIA bill that reauthorizes the Rehabilitation Act, including vocational rehabilitation (VR) programs. Harkin worked on a bipartisan basis to make improvements to the Rehabilitation Act—Title V of WIA—aimed at making sure that young people with disabilities have increased preparation and opportunities for competitive, integrated employment. The bill requires state VR agencies, in conjunction with local educational agencies, to make “pre-employment transition services” available to students with disabilities.

The bill will also require individuals under the age of 24 with a significant disability to make a serious attempt at competitive, integrated employment—including getting pre-employment transition services and utilizing VR services—before he or she can consider working at a segregated workshop or sheltered employment setting.

[Read more](#)

Quotable

"Great minds discuss ideas; average minds discuss events; small minds discuss people." - Eleanor Roosevelt

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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's 2014 ANNUAL CONFERENCE AND INITIATIVE * June 8 - 11, 2014 * Washington, D.C.**

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

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