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*Speaking out for people with
intellectual & developmental
disabilities*



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March 5, 2015

VOR Weekly News Update

News and views for VOR Advocates

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VOR and YOU

1. VOR 2015 Annual Conference Speaker Feature: Lois Sheaffer

Lois Sheaffer will be presenting "Everyone Needs a little REST!" at [VOR's 2015 Annual Conference](#) on Sunday, June 7, 2015 in Washington, D.C.

Ms. Sheaffer is the Founder, National Director and Master Trainer of Respite Education & Support Tools (REST). She also serves as the Director of Government Relations and Community Support for Marklund, a Medicaid Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) in Illinois.

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REST is a nationally-recognized train-the-trainer program that equips volunteers with the skills needed to support caregivers in their community through respite.

Ms. Sheaffer, a Certified Therapeutic Recreation Specialist, began her career in respite working with individuals who have special needs. As the coordinator of an in-home community respite program she hired, trained, and matched workers with families. She later became active in the Illinois Respite Coalition and served as President of the Coalition for five years. She continues to stay well connected with ARCH [Access to Respite Care and Help] and the National Respite Coalition.

Most recently, using the national respite guidelines, she developed REST, a respite training program for volunteers.

In addition, Ms. Sheaffer, has worked in a variety of settings, including geriatrics, skilled care, and pediatric residential facilities for children and adults with Developmental Disabilities. Lois is a registered lobbyist and currently serves as the Director of Government Relations and Community Support for Marklund.

Please plan to attend VOR's Annual Conference and hear Ms. Sheaffer's presentation. Won't you join us? Registration is now open.

For complete conference details and a registration form, visit [VOR's Events link on our website](#).

DEFINING COMMUNITY

2. New Housing Concept Emerging For Those With Disabilities

Disability Scoop * March 2, 2015

To be built on property acquired from the Florida Fish and Wildlife Conservation Commission, the new development known as The Villages at Noah's Landing shares with a similar project soon to break

ground in Jacksonville the distinction of being the first communities of their type in Florida.

Financed primarily with low-income housing tax credits, the project is expected to alleviate a waiting list for safe, affordable housing for adults with developmental disabilities such as autism, Down syndrome and cerebral palsy. Unlike state licensed group homes, Noah's Landing will operate independently, with oversight provided by staff, volunteers and parents, along with monitoring from state social workers.

It's a concept gaining acceptance nationwide, providing a stimulating community setting for people with intellectual and developmental disabilities who are capable of living with some degree of independence.

Noah's Landing will be composed of one-, two-, three- and four-bedroom apartments. Additional phases will include more housing, an assisted-living facility, fishing dock and recreational areas. Ultimately, the community could house up to 224 individuals.

Across the state, a community similar to Noah's Landing — The Arc Village — is preparing to break ground on the outskirts of downtown Jacksonville. It, too, is benefiting primarily from federal low-income housing tax credits, said Jim Whittaker, president and CEO of The Arc Jacksonville.

[Read more, comment and share](#)

3. NEW JERSEY: Gov. Christie will remove quotas from disability housing plan but defends 'Return Home N.J.'

NJ.com * March 4, 2015

Gov. Chris Christie said today he would remove strict limits on where people with developmental disabilities live and work that are contained in a proposal drafted by his administration to promote community integration [the State's proposed CMS Transition Plan], but he won't back off from a plan to return some 500 disabled people from out-of-state facilities.

"I've already said no to the draft transition plan," said Christie, noting he has received many calls and emails from worried families. The crowd applauded. But he cautioned that the decision was not entirely his to make. He urged residents to contact their members of Congress to tell them that "New Jersey's plan is too strict to be workable."

However, the governor vigorously defended his call to return more than 500 disabled people from out-of-state facilities, even if done over the protestations of parents.

[Read more, comment and share](#)

[Read VOR and our affiliate's comments opposing quotas and more in New Jersey's proposed State Transition Plan](#)

QUALITY IN THE COMMUNITY?

4. Failing Marci: A disabled woman's story of triumph and tragedy

Fort Worth Star-Telegram * February 27, 2015 * 2 part series

Marci Garvin depended on others to help her live life to the fullest, but the same people who supported her may have contributed to her death.

Born with numerous disabilities, including cerebral palsy, Marci was deaf, mostly blind and unable to talk.

She was one of a handful of people with severe or significant disabilities nationwide to find employment in the late 1990s, according to Michael Callahan, president of Marc Gold & Associates, a consulting company that trains agencies, systems and families in working with the significantly disabled.

When Marci died in the spring of 2013, however, the 39-year-old's final months painted a far different picture. When she was hospitalized on March 9, 2013 — two days before her death — nurses counted more than 20 major bedsores. Marci was covered in urine, feces and bugs. She weighed 50 to 60 pounds, almost half her normal weight.

Adult Protective Services and the inspector general's office launched investigations, and ultimately Marci's father, Mike Garvin, and older sister, Tabby Martinjak, were indicted on charges of injury to the disabled. Their cases are pending.

But the investigation indicates that others may have failed Marci, too. Enrolled in Home and Community Based Services, a Medicaid-funded program, Marci had been receiving help from private service providers and MHMR of Tarrant County.

[Read more, comment and share](#)

[Read Part 2: Failing Marci: Investigation raises questions about care and oversight for disabled woman](#)

5. States Strive to Keep Medicaid Patients Out of the Emergency Department

Stateline * The Pew Charitable Trusts * February 24, 2015

Nearly half the states use higher copayments to dissuade Medicaid recipients from unnecessary visits to emergency rooms, where care is more costly.

These states require patients to make the payments, which are as high as \$30 per visit in Oklahoma, when it is later determined that they did not experience a true medical emergency.

But at least one multistate study has found that charging higher copayments does not reduce emergency department (ED) use by Medicaid recipients. One reason might be that copays are hard to enforce, since EDs are legally obligated to examine anyone who walks through the doors, whether or not they can pay.

ED doctors and others in health policy also criticize copays as potentially dangerous, since they may lead people to think twice about seeking emergency care when they really need it.

[Read more, comment and share](#)

STATE NEWS

6. NEW JERSEY Department of Human Services in flux, needs strong new leadership

Star-Ledger * Opinion Editorial by Assemblywoman Valerie Vainieri Huttle

[Excerpts](#)

The recent departure of New Jersey Department of Human Services (DHS) Commissioner Jennifer Velez leaves our state at a crossroads and the futures of our most vulnerable residents at stake.

Some of the most substantial hurdles for the department lay in how to serve individuals with developmental disabilities. The Division of Developmental Disabilities claims that its mission is person-centered planning, focusing on giving people choice and options in where they live and how they spend their days. However, the division's actions during the past several years are evidence to the contrary.

Some troubling examples of this are the closure of the two North Jersey developmental centers and the Return Home NJ initiative, which is uprooting many individuals who have been receiving specialized care out of state for years, much to the consternation of their families. However, the most blatant instance is the Statewide Transition Plan.

[Read more, comment and share](#)

[Read and comment on related article about Commissioner Velez's departure and her record with regard to serving profoundly disabled citizens](#)

7. ILLINOIS: Murray Center Advocates Get First Meeting With Governor Rauner's Staff

WJBD News * March 1, 2015

Supporters of Murray Center say they were greeted warmly and asked for ideas as they sat down for the first time with officials of the administration of Governor Bruce Rauner on Thursday.

The President of the Murray Parents Association Rita Winkeler is very happy after the meeting that included Governor Rauner's Special Counsel and

Advisor on Healthcare and Human Services Jennifer Hammer.

"I feel very confident they really are wanting to keep Murray Center open. They are looking for ideas that we do to make Murray Center even better. They are very open to ideas. It was a wonderful visit because they actually listened to us. They asked us to get back in contact with them with some other ideas we have been working on. It's much more of an open door policy. They don't have a set agenda. They are really willing to listen to people," said Winkeler. "I think it was a very good meeting."

[Read more, comment and share](#)

8. VIRGINIA: Leaving the Most At-Risk by the Road

The News & Advance (Lynchburg, VA) * February 27, 2015

As the General Assembly entered its final week Monday, it became obvious legislators would again fail to address the concerns and fears of parents and guardians of residents of the commonwealth's four residential training centers for the developmentally and intellectually disabled.

Guardians of many training center residents are understandably worried about futures of their loved ones and their wards. Many adult residents have lived in a training-center setting since they were children; it's the only home they've known. Many of the remaining training center residents are the people requiring the most intense, 'round-the-clock care in a hospital-type setting. And many are among the people with the most profound and severe challenges.

Under the terms of the consent decree, these residents would transition to community-based group homes where, ostensibly, they would receive the exact level of care as they would in a training center, though at a substantially lower cost to the state.

Except — and here's the scary part for guardians and families — the needed group home infrastructure in the commonwealth simply does not exist. Currently, there are thousands of people on the state's waiting

list for a group home spot. And that waiting list has only grown in the three years since the McDonnell administration decided to embark on the closure of the training centers, a path chosen because Richmond didn't want to spend any additional money to build out the group home network before the training centers would close.

[Read more, comment and share](#)

9. SOUTH DAKOTA: Special Needs Registry Created To Help Find Missing Children

*KDLT News (Sioux Falls, SD) * March 3, 2015*

One in every 68 children in the United States is diagnosed with Autism Spectrum Disorder. According to a recent study, nearly half of them are prone to wandering.

Sioux Falls Police say if and when that happens, they want to be able to find them as quickly as possible. They created a registry to make it easier to locate children with special needs. On the department's website, parents can now submit information about their child, along with pictures. A questionnaire asks very detailed questions.

[Read more, comment and share](#)

MENTAL HEALTH IN THE NEWS

10. Should Mentally Ill People Be Forced Into Treatment?

*Time Magazine * February 20, 2015*

A new study finds that involuntary psychiatric treatment programs can keep people from cycling through ERs, jails, prisons, and homeless shelters—and therefore save taxpayers gobs of money. Is it worth it?

[Read more, comment and share](#)

11. Author talks about mental health crisis in Louisiana and nation

*The Advocate (Baton Rouge, LA) * February 28, 2015*

Even with ample means, connections and

determination, Pete Earley initially couldn't force his unwilling son into treatment during a mental health breakdown in Virginia because he wasn't obviously threatening "imminent danger" to anyone else. So when his son was jailed and charged with breaking and entering after being found taking a bubble bath in a stranger's home during a subsequent mental health crisis, Earley grew angry.

"The law kept me from getting him help," Earley said, "and then it wanted to punish him."

Kevin Earley's path through the complex and increasingly overlapping mental health and criminal justice systems later became the subject of Pete Earley's best-selling book, "Crazy: A Father's Search Through America's Mental Health Madness." It was the main topic of discussion when the former Washington Post reporter spoke Thursday night in downtown Baton Rouge as part of the Baton Rouge Area Foundation's ongoing campaign to raise awareness about the need for improved mental health treatment in the capital region.

[Read more, comment and share](#)

AUTISM IN THE NEWS

12. Training Aims To Tackle Autism Knowledge Gap Among Doctors

Disability Scoop * February 24, 2015

A new effort is in the works to help train doctors and other health care providers to better serve individuals on the spectrum.

Using web conferencing and other virtual technology, the first-of-its-kind training program will bring working physicians together with autism experts for biweekly, two-hour sessions in order to learn about the developmental disorder and commonly associated issues like constipation and sleep difficulties.

[Read more, comment and share](#)

QUOTABLE

"Today is your day! Your mountain is waiting so get

on your way!" ~ Theodor Seuss Geisel

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Calendar Reminders:

Tuesday, March 24, 2015:

**[American Health Care Association ID/DD
Washington Fly-In](#)**

Congressional speakers are being invited, a legislative update will be provided, and Hill visits will follow in the afternoon. Breakfast and a boxed lunch will be provided to you. **[Registration is free but required.](#)** VOR members are encouraged to attend.

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.

VOR
836 S. Arlington Heights Rd., #351
Elk Grove Village, IL 60007
Email: info@vor.net

Tel: (605) 399-1624
Toll Free: (877) 399-4867
Fax: (605) 399-1631

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