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April 18, 2014



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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**Coming Soon: VOR Action Alert - Time Sensitive
Watch for it!**

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Calendar Reminders

VOR and You

1. Annual Conference Registration: Register today to save. June is approaching quickly!

Thanks to the many advocates who have already registered! We can wait to see you in Washington, D.C.!

This is going to be a great conference with great networking and speakers. You can see [all details for our Washington, D.C. event on VOR's website](#), including dates, agenda of speakers and events, and [hotel reservation](#) information.

Some deadlines are approaching:

May 1: Annual Conference Registration Deadline (prices increases after May 1). Register [online](#) or by [mail/fax/email](#).

May 5: [Hyatt Hotel Reservation](#) Deadline to guarantee group rate and availability. All VOR events take place at the hotel.

Make your plans today. See you in June!

2. VOR Press Release for April Autism Awareness Month

VOR * For Immediate Release: April 15, 2014

In Recognition of Autism Awareness Month, VOR Speaks Out About National Crisis: A Lack of Choice. Quality

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About VOR

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and True Person-Centered Care For The Disabled

Elk Grove Village, IL – April 15, 2015: Across the country, tens of thousands of individuals with developmental disabilities, including autism, are suffering due to lack of access to appropriate care and services.

The numbers representing present and future need are alarming. Almost all states have waitlists for accessing adult support services, with more than 280,000 individuals with developmental disabilities, including autism, going without necessary care in 2013. Almost one million individuals with developmental disabilities, including autism, are still living with caregivers over the age of 60. In the next decade, over 800,000 on the autism spectrum will transition to adulthood.

So where do we go from here?

[Read more and share with local, state and national media](#)

3. VOR Submits Testimony for Record Asking Congress to Prohibit Federal Funding for Forced Deinstitutionalization; Hundreds of Choice Advocates Share Their Support

VOR is a national organization that advocates for high quality care and human rights for all people with intellectual and developmental disabilities (I/DD). VOR calls on Congress to prohibit the use of U.S. Department of Health and Human Services' (HHS) appropriations in support of deinstitutionalization activities which evict eligible individuals with I/DD from their HHS-licensed and funded Medicaid homes, in violation of federal law.

588 advocates for family members and friends also submitted a statement for the record in support for VOR's testimony, and many others submitted their own testimony.

[Read VOR's complete testimony here](#)

STATE NEWS

4. Illinois: Opponents of Murray center closure win round in court

Quad City Times (Springfield, IL) * April 16, 2014

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About VOR

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A state appeals court has ruled in favor of a group of parents trying to stop Gov. Pat Quinn from closing a state-run developmental center in Centralia.

In a decision released Wednesday, the 5th District Appellate Court in Mount Vernon turned back attempts by Illinois Attorney General Lisa Madigan's office to dismiss the case.

[Read more, comment and share](#)

5. Georgia: Report - Need Better Care for the Developmentally Disabled

Georgia Health News * April 10, 2014

An independent reviewer, assigned by the Court to oversee the Department of Justice and the State, reports that Georgia is failing to provide adequate supervision of individuals with developmental disabilities who are moved from state hospitals to community group homes. [The Settlement calls for the closure of all hospitals (ICFs/IID) for people with intellectual and developmental disabilities].

The reviewer, in a report dated March 23, says there is an “urgent need to ensure competent and sufficient health practitioner oversight of individuals who are medically fragile and require assistance with most aspects of their daily lives.”

The reviewer, Elizabeth Jones, notes in the report that two individuals with developmental disabilities died shortly after being moved from Southwestern State Hospital in Thomasville, which recently closed, to community settings.

The report also points out that state officials terminated three providers of services for poor quality of care.

Meanwhile, the state announced that the current head of developmental disabilities services, Dr. Charles Li, will return to his former job as director of hospital operations, and that Dan Howell will serve as interim assistant commissioner of the Division of Developmental Disabilities as a national search for Li's successor takes place.

The turnover shows a lack of stability, said Eric Jacobson, executive director of the Georgia Council on Developmental Disabilities. “That leads to a lack of vision and leadership to determine where we’re going.”

He said the individuals being moved out of hospitals now “are the most medically fragile. They

will be the most difficult individuals for the state to transition into the community.” Georgia’s service providers currently “don’t have the capacity to support these individuals,” Jacobson said.

He nevertheless reiterated his support of the settlement goal to move all people with developmental disabilities into community settings. “We believe no one should be living in an institution.”

[Read more, comment and share](#)

[Related NPR Story: State Suspends Transfers of Developmentally Disabled Patients into Community Settings](#)

[Related Union-Times News Story: Craig Center closing postponed again; Independent review says better supervision needed](#)

6. Virginia: Governor McAuliffe signs SB 627, new to assure better care for training center residents

On April 4, 2014, Governor Terry McAuliffe signed Senate Bill (SB) 627 into law, effective July 1. The key provisions of SB 627 – “An Act to ensure adequate resources are available and disclosed to training center [public ICFs/IID] residents prior to their transfer to another training center or community-based care” -- require the Virginia Department of Behavioral Health and Developmental Services (DBHDS) to:

1. Certify, before any resident is transferred to either the community or another Training Center, that the receiving placement “provides a quality of care that is comparable to that provided in the resident’s current training center regarding medical, health, developmental, and behavioral care and safety.”
2. Disclose “all permissible placement options available under the Commonwealth’s August 23, 2012 settlement agreement with the U.S. Department of Justice, including the option to remain in a training center.”
3. “Convene a work group of interested stakeholders, which shall include members of the General Assembly, to consider options for expanding the number of training centers that remain open, in whole or in part, in the Commonwealth.”

[Read SB 627 Enrolled \(April 4, 2014\)](#)

7. California: Close to Home - Agreeing on a vision for the future of Sonoma Developmental Center

The Press Democrat * Commentary by Susan Gorin.

Sonoma County Board of Supervisors (1st District)

Sonoma County is unique in many ways: our environment, our compassion, our commitment to community. Most notable is our ability to turn challenges into opportunities as we forge a sustainable future for our children.

We are again at a crossroads, facing a challenge that requires communal courage as we navigate the threat of closure of the Sonoma Developmental Center. It is not enough to hope the state of California will do the right thing; instead, we must demonstrate the dedication of our community for the humane treatment of our most vulnerable population, as well as our commitment to preserving the bucolic lands that surround the center.

The Parent Hospital Association, Sonoma Land Trust, Sonoma County's Regional Parks Department, Agricultural Preservation and Open Space District and local grass-roots preservation groups have joined together in a broad-based community collaboration to develop a vision for the future that preserves the services and the land for future generations. This collaborative vision includes continuing services onsite for residents, developing complementary services to our community and providing public access to the preserved undeveloped land.

[Read more, comment and share](#)

8. North Jersey's disabled and their families are *forced* to move on

***NorthJersey.Com* * April 13, 2014**

With the state-run residential centers for the disabled slated to close in northern New Jersey, hundreds of families are searching for new homes for their loved ones.

The decision is tearing at many families who worry about how they will maintain contact if a loved one is moved to an institution hundreds of miles away — a trek especially daunting for aging parents. Others, however, have discovered they are pleased with local group homes, which they never thought would have sufficed in the face of extreme disabilities.

[Read more, comment and share](#)

9. Tennessee: Legal concerns raise treatment costs for developmentally and intellectually

disabled

The Tennessean * April 14 2014

Decades ago "Tennessee went kicking and screaming into deinstitutionalization and spent a fortune battling it out in court when other states moved ahead," said Deanna Claiborne, executive director of United Cerebral Palsy of Middle Tennessee. "The system we're stuck with now was not created by citizens and legislators and family members and experts deciding what is best. Tennessee's policy was set by judges who said, 'You cannot continue to behave this way.'"

This year, the state has a chance to modify its system, submitting a new plan to federal authorities on how Tennessee will care for people with intellectual disabilities. State officials and advocates say they are considering new ways to provide less costly services to more people, but with a limited budget increase approved this year, advocates say it is unlikely the system can change substantially.

"When they are transitioned into the community, there is often an expectation — particularly under the heightened scrutiny of court monitors and others — that the intensive level of staffing and supports provided in the institution is replicated in the community," said Patti Killingsworth, director of long term care.

State officials are working with advocates to create a more balanced system. They have already placed a 12-hour per day limit on the time one nurse cares for an individual and have limited personal assistance services to 215 hours per month to reduce costs, and relying on more technology, like cameras in lieu of 1:1 staff.

Killingsworth said the state also is considering a monetary cap for services provided to each individual. Currently, most of the 8,000 people receiving state services have no individual cost limits.

[Read more, comment and share](#)

10. Oregon: Thousands of disabled Oregon workers could be impacted by the U.S. settlement in Rhode Island

The Oregonian * April 8, 2014

The government's landmark Americans with Disabilities Act settlement with Rhode Island on Tuesday is expected to move people with profound disabilities out of low-paying jobs in sheltered workshops into the general workforce, a move federal lawyers are calling a blueprint for the nation.

Senior lawyers in the Justice Department say the settlement will serve as a model for Oregon and other states abundant with workshops and activity programs for disabled adults that keep them segregated from the greater world of commerce.

[Read more, comment and share](#)

IMPORTANT: RESPOND TO THIS POLL

Read Related: VOR's Position on Employment Choice:

“VOR supports a full array of employment options, including sheltered workshops, supported employment, and competitive employment based on individual abilities. People with intellectual or development disabilities (I/DD), have a right to choose where they work and where they live.”

GREAT LETTERS TO THE EDITOR

11. Illinois: Too little data to decide on placements for disabled adults

Belleville News Democrat * April 14, 2014 * Letter to the Editor by Laurie Stengler
(www.MurrayParentsAssociation.com)

Families and legislators need accurate information to make informed choices regarding care for the disabled.

An evaluation of the Jacksonville Developmental Center Closure (preliminary results) was released in March. In a discussion on the ARC website, Tony Paulauski notes that 89.2 percent of the guardians reported that they were somewhat/very satisfied with their ward's living situation. He notes that as he expected, "the findings are very similar to other studies of institutional closures in Illinois and other states." Readers who do not investigate further will see this as success. This is not a proper conclusion and is misleading.

Only 65 (36 percent) of guardians responded to the

survey. That is hardly large enough to make any conclusions regarding the 178 individuals transitioned from Jacksonville. Note that 113 (64 percent) of residents transitioned out of Jacksonville are not accounted for. We need to account for all the residents. How many are in other state developmental centers? How many tried community settings only to be sent back to a state center? How many are homeless and using services in Jacksonville or other community shelters? How many have had reports of abuse or neglect or died?

If the state is doing followups as it has stated it would do, where is the data? The existing data is inconclusive at best. It does not seem unreasonable to expect a full accounting of the Jacksonville transition before subjecting Murray Center residents to the same.

[Read more, comment and share](#)

[See Related Letter to Editor: Can't count on Illinois to protect the disabled \(Karen Kelly, April 14, 2014\)](#)

12. New Jersey: Centers for disabled should not close

***North Jersey.com* * April 14, 2014 * Letter to the Editor by Hedy Grant, Councilwoman, New Milford, NJ**

Regarding "Anguish grows for families of disabled" (Page A-1, April 14): It is not easy to have a disabled child. State-provided assistance goes a long way to making a difficult situation a little easier. The current plan, which will close two developmental centers in northern New Jersey, is unconscionable, as it will put unnecessary and excessive burdens on families who wish to stay in touch with their institutionalized adult children.

At least one of the two centers scheduled for closing should remain open. I urge the governor to have compassion for these families instead of saying that he won't allow "a vocal minority to stop progress." Closing these two centers while keeping those in southern New Jersey open is not progress, at least not for families in northern New Jersey.

[Read more, comment and share](#)

APRIL IS AUTISM AWARENESS MONTH

13. Study Finds Inpatient Autism Treatment On The Rise

Disability Scoop * April 15, 2014

The number of children with autism who are being hospitalized — often due to mental health concerns — is on the rise, particularly among teens with the developmental disorder, new research suggests.

In a study looking at data on over 2 million hospitalizations of California children ages 1 to 18, researchers at the Stanford University School of Medicine found that between 1999 and 2009, inpatient treatment related to autism nearly tripled.

The rise came as the number of hospitalizations related to other developmental disabilities including cerebral palsy, Down syndrome and intellectual disability remained largely steady, according to [findings](#) published in the May issue of the Journal of Autism and Developmental Disorders.

While the risk of hospitalization rose for kids with autism across all age groups, researchers found that the increase was most pronounced for those older than 11. Once children reached the ages of 15 to 18, individuals with autism were three-and-a-half times more likely than their peers without the developmental disorder to be hospitalized, the study found.

In all but the youngest children studied, mental health diagnoses were the most common reason those with autism were treated.

It's unclear what precisely is driving the growth in hospitalizations, but researchers said that it could be due to a lack of outpatient and community resources as the number of people with autism has grown.

“Overwhelmed parents, schools and community providers of mental health resources may have been unable to meet the needs of these patients and this failure to treat adequately in the outpatient sector may have led to a direct increase in hospitalizations,” the study authors wrote.

[Read more, comment and share](#)

14. Groups Want Federal Autism Dollars Reallocated

Disability Scoop * April 11, 2014

With the nation's primary autism legislation set to expire soon, some disability advocates are pressing for major changes in the federal government's approach to the developmental disorder.

In a letter this week to key members of Congress, 18 national organizations are asking for a greater emphasis on services and the needs of adults with autism when lawmakers reauthorize legislation known as the Combating Autism Act.

"Congress should make common-sense changes that will ensure that federal funds are better used to benefit the community that this legislation is designed to serve," wrote the Autistic Self Advocacy Network, the Autism Society of America, the American Association of People with Disabilities, TASH, the National Disability Rights Network and other groups in the letter.

[Read more, comment and share](#)

Quotable

"Power concedes nothing without a demand. It never did and it never will." ~ Frederick Douglass

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Calendar Reminders:

VOR Annual Conference Deadlines Approaching:

May 1: Annual Conference Registration Deadline (prices increase after May 1). Register [online](#) or by [mail/fax/email](#).

May 5: [Hyatt Hotel Reservation](#) Deadline to guarantee group rate and availability. All VOR events take place at the hotel.

June 8, 2014

VOR 2014 Annual Conference and Initiative:

"Making it Happen: Reforming Policy and Law in Support of Person-Centered Quality and Choice"; Hyatt Regency, Washington, D.C.

[Register today!](#)

Week of June 9, 2013

VOR 2014 Congressional Initiative: Families and advocates visit Capitol Hill.

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 will open in Spring 2014.

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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