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April 4, 2014



Speaking out for people with
intellectual & developmental
disabilities



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**Reminders:
Help VOR Grow!**

VOR Weekly News Update

News and views for VOR Advocates

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VOR and You

1. It's not too late to join us in D.C. Register today!

The VOR's 2014 Annual Conference, Making it Happen: Reforming Policy and Law in Support of Person-Centered Quality and Choice, is coming up quick!

Have you registered yet?

When Sunday, June 8, 2014 arrives we hope you will be by our side. There is always great networking and speakers, and following the conference you can also participate in VOR's Washington Initiative, which includes Congressional visits, during the week of June 9, 2014. For more information, including registration opportunities, visit VOR's website.

What are you waiting for?

- **[Here is an online registration form.](#)**
- If you prefer to respond by mail, **[here is a print form with conference details and registration form to mail.](#)**
- **[Here is a link for hotel reservations.](#)**

Please **[register today](#)** and see you in June!

Gratefully,
VOR

Questions: thopp@vor.net

Share: Please share **[information about our Conference](#)** with your family and friends by email and on social media. Thank you!

2. VOR's 2014 Press Kit Published

Reminders: Help VOR Grow!

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[VOR's 2014 Press Kit](#), a collection of written materials designed to introduce VOR to the media and others, is now available.

You are encouraged to share VOR's Press Kit, or select documents from it, with your media contacts, advocates and others.

3. *Home is Where the Heart Is: The Coalition for Community Choice - A unified voice for increasing options and decreasing barriers to housing choices*

EP Magazine (April 2014) * By Tamie Hopp, VOR and Desiree Kameka, Madison House Autism Foundation

Did you know...

- In the next decade, over 800,000 on the autism spectrum will transition to adulthood.
- Almost all states have waitlists for accessing adult support services, yet the average growth of funding nationally is only 3.2%.
- Almost one million individuals with intellectual and/or developmental disabilities (I/DD) are still living with caregivers over the age of 60.

In response to these staggering statistics, there is a movement of families and local organizations working together to create sustainable solutions to this national housing and support service crisis. They are organized and gathering information at conferences, many have joined together for advocacy as the [Coalition for Community Choice](#), and are sharing solutions at the new [Autism Housing Network](#) .

[Read more and share](#)

[Read full article \(EP Magazine, April 2014\)](#)

[Click here for more information about EP Magazine](#)

4. April is Autism Awareness Month: Opportunity for Input from Dateline NBC

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In recognition World Autism Day (April 2) and Autism Awareness Month (April), Dateline NBC is asking you to tell us how autism has affected you. What do you want to tell us about autism?

Here's how to tell us:

On Facebook: go to the [Dateline NBC page](#) and leave a comment under the post asking how autism has affected you:

On Twitter: go to the [Dateline NBC twitter account](#) (@DatelineNBC) and retweet our post asking how autism has affected you and hashtag your response #Dateline and #DatelineNBC

Please share this with your family, friends, colleagues, teachers, case workers, support staff, aides, physicians, and anyone whose life has been touched by autism. Offer your posts throughout the month of April, Autism Awareness Month.

STATE NEWS

5. New Jersey: Old Bridge parents fight daughter's move from Woodbridge Developmental Center in court

MyCentralNJ.com * April 3, 2014

Frances and Thomas Kauffman can't understand why there seems to be a rush to relocate their daughter, Theresa, from the Woodbridge Developmental Center, where she has lived for 32 years, when the facility isn't scheduled to close until the end of this year.

They have taken their fight to court.

[Read more, comment and share](#)

6. Illinois: More People In Jacksonville Homeless Shelter Suffering From Mental Illness

ABC News Channel 20 * April 1, 2014

[Watch Newscast Video](#)

A year after the closure of the Jacksonville Developmental Center, officials say some of those people haven't handled the transition well and are finding themselves on the street.

The director of a homeless shelter in Jacksonville

says she's seeing more and more people coming in with some form of mental illness. It's ranging from mild depression to more severe forms, like PTSD. Part of the reason for the increase, some officials believe, is due to the closure of the Jacksonville Developmental Center, and other mental health facilities within the last year.

[Read more, comment and share](#)

7. Kentucky: Adult Protection Registry Bill Passes!

Kentucky Senate Bill (SB) 98, the bill that provides Kentucky with the Adult Protection Registry, has passed. It now heads to the Governor for his signature.

SB 98 creates an adult protection registry. By creating a registry, the bill would prohibit caregivers who have abused, neglected, or exploited adults with disabilities (including elders) while working in the field from abusing others who are vulnerable. Importantly, the bill would also establish due process protections for alleged perpetrators. Sen. Sara Beth Gregory (R-Monticello) is the sponsor of SB 98.

A related Kentucky bill, House Bill (HB) 277 did not pass, but plans are already underway to press forward in future sessions. HB 277 would have mandated fingerprint checks, abuse registry checks and a check of professional licensure board information as part of a National and State Background Check Program. Those who appear on a registry, whose professional license is not in good standing, or who are otherwise disqualified based on the state's determination would be prohibited from working with long-term care facilities and providers or from performing state inspections of such workplaces, according to the legislation.

8. Illinois: Demand Soars For Special Education Boarding Schools

Disability Scoop * March 28, 2014

Increasing autism rates and rising mental health issues among children are causing a spike in the

number of public school students attending residential treatment centers, boarding schools that combine education with intense therapy.

Many parents say these schools have performed wonders for their children, helping them back from the brink of dysfunction, despair, even suicide. But the high cost and soaring need have prompted some experts to warn that the service could be in jeopardy.

In Illinois, the state has informed local school districts, which pay much of the tab for their students' stays, that demand for the boarding schools has outrun the money set aside to pay for them. That means districts will have to bear extra costs themselves — costs that can amount to hundreds of thousands of dollars a year.

School officials say finances will not influence their decisions on whether to send children to residential facilities, but some observers are skeptical.

[Read more, comment and share](#)

9. Georgia Legislature Passes Bill Revising Functions of Department of Behavioral Health and Developmental Disabilities (DBHDD) in Effort to Protect Public Safety Net for Services

Georgia Senate Bill 349, which revises the functions and responsibilities of the Georgia Department of Behavioral Health and Developmental Disabilities (DBHDD), has passed both chambers and is now awaiting signature by Governor Nathan Deal. The bill was sponsored by Senator Charlie Bethel (R-Dalton) on behalf of Governor Deal.

"The intention of SB 349 is to enhance the quality of the services provided by DBHDD, as well as create a state public safety net program, following the recent transition from institutional care to community care in Georgia," said Sen. Bethel. "These changes are meant to strengthen the methods and delivery of disability services throughout Georgia."

SB 349 amends Georgia code and revises the administration of mental health, developmental disabilities, addictive diseases, and other disability services provided by DBHDD. The bill also establishes governing boards and also clarifies the powers and duties for every community service board

(CSB) in the state.

On March 13, DBHDD Commissioner Frank Berry announced a moratorium on transitions of individuals with intellectual and developmental disabilities (I/DD) from state-operated facility homes to community settings. “[W]e are we are assessing the unique needs of all individuals with developmental disabilities currently residing in our hospitals. Consequently, we have made the decision to suspend patient transitions into community-based settings.” Commissioner Berry’s announcement follows a Justice Department moratorium on such transitions and a critical Quality Management Report for 2013.

10. Pennsylvania: Pennsylvania: Commissioner stresses value of state hospitals

*Times Leader (Wilkes-Barre, PA) * April 2, 2014*

After the announcement of the planned removal of 14 beds at the Clarks Summit State Hospital during a Fairchild Hearing March 25, Lackawanna County Commissioner Patrick O’Malley believes more beds, not less are needed at the facility.

“I have spoken to different psychologists and doctors who said there is absolutely a need for state hospitals,” O’Malley said. “A state hospital is an option we should have in the community.

While O’Malley can understand transitioning some individuals struggling with mental illness back into the community, he feels there is still a need for others to receive the care and structure offered at a state hospital.

[Read more, comment and share](#)

FEDERAL NEWS

11. IRS Says It Will Treat Difficult of Care Payments to Family Members as Tax Exempt

Federal Perspectives ([NASDDDS](#)) * February 2014

The Internal Revenue Service (IRS) has issued a notice providing that the IRS will treat qualified Medicaid waiver payments for care provided to any individual who is living in a “foster family home” in

which the individual was “placed” by an agency of a state or a political subdivision thereof, or a qualified foster care placement agency, as difficulty of care payments, which excludable income under Section 131 of the IRS Code even if the care provider is a family member. This reverses a previous IRS position that a caregiver of a biological relative receiving qualified Medicaid waiver payments may not qualify as a foster care provider under Section 131. This notice reserves that position, meaning that stipends to family members to meet the cost of supports provided to their adult family members who live with them can now be treated as tax-exempt.

[See IRS Bulletin here](#)

Quotable

"If you hit the target every time it's too near or too big." ~ Tom Hirshfield

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Calendar Reminders:

Tuesday, March 25, 2014

[AHCA/NCAL's fifth annual "ID/DD Residential Services Providers Hill Fly-In."](#) Questions? Dana Halvorson, dhalvorson@ahca.org.

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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