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Speaking out for people with intellectual & developmental disabilities

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Reminders:
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February 13, 2015

VOR Weekly News Update

News and views for VOR Advocates

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1. Guardianship Under Attack: Your Comments Needed

On January 28, 2015, the Administration on Community Living (ACL) within the U.S. Department of Health and Human Services (HHS) published a blog article titled, “Preserving the Right to Self-determination: Supported Decision-Making.”

In sum, the article encourages a supported decision-making process in lieu of legal guardianship. Unlike legal guardianship, supported decision-making is described as less formal and more flexible. In fact, it is the legal guardianship process that troubles Commissioner Bishop. He states that "The trouble with guardianship is that it is a legal process" and incorrectly indicates that the legal approach "assumes that people with disabilities and older adults are incapable of making decisions." In fact, the opposite is true: Guardianship requires a legal process to protect against unnecessary guardianships and begins with the presumption that everyone is legally competent until determined otherwise by a court of law.

In response to this blog, some commenting, including VOR members and families, have expressed alarm at the implication that supported decision-making should replace legal guardianship, especially for individuals with profound intellectual disabilities.

Guardianship is not the default position; doing nothing is. Guardianship only occurs after a court has determined the need for it and appointed an appropriate person.

You are strongly encouraged to COMMENT.

Read more, COMMENT and SHARE

STATE NEWS

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About VOR

2. Wisconsin: Madison Symphony Orchestra strikes a chord through HeartStrings

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***Madison Magazine* * January 20, 2015**

HeartStrings is a community engagement program that brings live, interactive music performances—by some of the Madison Symphony Orchestra's top musicians—to health care and residential facilities to reach listeners of all ages, most of whom are challenged with physical and emotional disabilities of varying degrees. More than just a series of concerts, these visits have sparked extraordinary cognitive, emotional and physical changes in the audiences they've reached, and the impact on the musicians has been equally powerful.

Central Wisconsin Center (CWC) a state [ICF/IID] residential and treatment center for people with developmental disabilities, continues to be one of the ongoing venues for HeartStrings, which has touched more than thirty other countywide facilities, running the gamut from children's hospitals to retirement facilities to community centers, over the years.

Read more, comment and share

3. Ohio: State to close 2 residential centers for developmentally disabled

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***The Columbus Dispatch* * February 11, 2015**

A plan to close two more of Ohio's 10 residential centers for people with developmental disabilities reflects a national trend toward smaller-scale community living for those served by disabilities systems.

But there's disagreement over whether that quickening pace is welcome or worrisome.

VOR, a national advocacy organization that opposes eliminating institutional options, said the move to community-based care has spawned problems, too.

"There is a growing body of documentation that folks with very profound disabilities are not faring well in community-based settings," said **Tamie Hopp**, VOR's director of government relations and advocacy. She said some areas have seen increased mortality rates, hospitalizations and injuries.

Read more, comment and share

Read worker response: Union outraged over disability center closure announcement

4. Ohio: Disability Advocacy Alliance Releases Comments to Final Report of the Ohio Department of Developmental Disabilities (DODD) Strategic Planning Leadership Group (SPLG)

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***DAA Press Release* * January 30, 2015**

Disability Advocacy Alliance (DAA) has released its comments in response to the Final Report of the Ohio Department of Developmental Disabilities (DODD) Strategic Planning Leadership Group (SPLG).

DAA, an all-volunteer organization, was formed by families of individuals with intellectual and developmental disabilities to protect the rights of vulnerable citizens with disabilities in Ohio.

DAA has grave concerns about the following SPLG recommendations which eliminate the right of individuals with intellectual and developmental disabilities (I/DD) to receive person-centered services and supports in the settings of their choice:

- "The total number of ICF beds is reduced by 50 percent, to 2800 beds."
- "1500 people will leave ICF facilities of 16 beds or larger and move to community homes. The average setting size of these community homes is four beds or fewer."
- "The number of people employed is 50 percent of the adults served."

SPLG's proposals do not follow the true meaning of the U.S. Supreme Court's *Olmstead* decision which affirms the need for a range of services to meet the diverse needs of people with intellectual and developmental disabilities (I/DD). *Olmstead* also makes clear that individual choice is paramount in determining residential and program placement.

DAA takes issue with SPLG's s cavalier approach to policymaking.

Read full press release and share

Read DAA Comments

5. New Jersey Senate panel OKs bill requiring state to follow up on ex-residents of closed developmental centers

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***The Record* * February 9, 2015**

A bill that would require the state to follow up on the former residents of a pair of shuttered developmental centers was approved by a Senate panel on Monday.

The bill, which has already been unanimously approved by the Assembly, would mandate the Department of Human Services conduct studies to assess the well-being of all individuals who have and will transition from the centers in Totowa and Woodbridge to the community. The center in Totowa closed last July, and Woodbridge closed last month. Both were recommended for closure by a state task force report in 2012.

The bill now heads to the full Senate for a vote.

Read more, comment and share

6. Illinois: Community Resource Associates (CRA) and 'Rent a Cops' Gone from Murray Center
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***WJBD News* * February 9, 2015**

Two controversial contract services have ended and some temporary positions are being made permanent at the Murray Developmental Center.

The President of the Murray Parents Association Rita Winkeler says Community Resource Associates (CRA) packed up and left the Murray Developmental Center and other locations in the state where CRA was trying to relocate residents to private care facilities on January 30th when its un-renewed contract ended.

Winkeler called the CRA contract a waste of $2-million a year that could have been better used to serve those on the waiting list for state services.

Winkeler says the 'Rent-a-Cops' security guards brought in by former Governor Pat Quinn's administration are also gone. She noted the 'unneeded service' in her opinion was costing the cash starved state $26,000 a month.

Also gone are the State Department of Human Services officials who were intent on closing Murray Center, despite the impact on the residents and the lack of adequate private facilities. Winkeler says they are now awaiting appointment of a permanent Director of Human Services so longer term issues can be worked out.

Read more, comment and share

CRA in Your State? Advocacy FYI: CRA (Derrick F. Dufresne and Michael Mayer) is a training and management consulting firm dedicated to promoting full community inclusion for people with disabilities.

AUTISM NEWS

7. Autism Speaks Putting New Focus On Adults

***Disability Scoop* * February 3, 2015**
After prioritizing the needs of children for years, the nation's largest autism advocacy organization is turning its attention to expanding housing options and supports for adults.

Starting as a pilot project in three states — Florida, New Jersey and Illinois — Autism Speaks is working with locally-based disability advocacy groups and policymakers to identify legislative goals and mobilize its own network to push for expanded home and community-based services

The initiative will be extremely state-specific given how unique each state's Medicaid program is, said Angela Lello, director of housing and community living at Autism Speaks. In some states, objectives will likely center on reducing the number of people on waiting lists for services while the focus in other places may be on expanding the availability of affordable housing or the types of supported-home environments that are offered to people on the spectrum, she said.

Read more, comment and share

8. More Differences Than Similarities Are Found in Autistic Siblings

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***New York Times* * January 26, 2015**

Most siblings with a diagnosis of autism do not share the same genetic risk factors for the disorder and are as distinct in their behaviors as any brothers and sisters, scientists reported on Monday in a **study** that came as a surprise to many doctors, if not to parents.

Scientists analyzed genetic material from 85 families, using a technology called whole-genome sequencing. Unlike other approaches, which illuminate a sample of a person's genetic material, the whole-genome technique maps out the entire voluminous recipe, every biological typo, every misplaced comma or transposed letter. Each of the families had two children with a diagnosis of autism.

Read more, COMMENT and share

QUOTABLE

"*You have to go wholeheartedly into anything in order to achieve anything worth having.*" ~ Frank Lloyd Wright

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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.

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