

August 8, 2014



Speaking out for people with intellectual & developmental disabilities



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VOR and YOU

1. Get Connected to VOR - Connect VOR with others!

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Share these opportunities and VOR information others!

Contact info@vor.net for more information or request that your friends and families receive this weekly publication directly!

2. Reminder: August is a great time for face time with YOUR members of Congress

From August 1 - September 7, Members of Congress will be from their State and District offices near your home. This is an incredible opportunity for you to meet face-to-face with your elected officials to share your perspective regarding the services and supports required by your family members and friends with intellectual and developmental disabilities.

[Click here for an Alert from VOR](#)

3. Karen Schupak receives Volunteer of the Year Award from Parents & Associates of Northern Virginia training Center

On August 6, 2014, Karen Schupak, Virginia Volunteer and VOR member, was presented with the Volunteer of the Year Award by the

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Parents & Associates of Northern Virginia Training Center (NVTC) at the Inter-Service Club Council of Fairfax City, Inc.

Citing her boundless energy, perseverance and sheer desire to make things happen, Karen was recognized in particular for a petition effort which secured 11,500 signatures from citizens across Virginia. She was determined to show Virginia's legislators and a new Governor that the concerns impacting citizens with intellectual and developmental disabilities – Virginia's "voiceless, vulnerable population" – were shared by more than just 800 families.

"Karen took the initiative, created a petition to educate thousands, rallied our volunteers with her passion and vision and followed it through until she gathered [more than her personal goal of] 10,000 signatures," said Jack Bruggeman, the Board Member for Parents & Advocates of NVTC parent who presented the award.

Karen's petition effort is credited in part for encouraging the Virginia legislature to study the closure plan for Virginia's training centers and for delaying the closing of Northern Virginia Training Center for at least one year.

Congratulations, Karen!

4. Employer Matching Gift Opportunities!

Did you know some employers match employee donations to nonprofit organizations?

Does your company match gifts?

If your company matches gifts or you know companies that do, please let Julie Huso know at jhuso@vor.net.

STATE NEWS

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5. Virginia: Training center debate heats up in Richmond

News & Advance * August 4, 2014

RICHMOND — Families connected to Virginia's centers for the disabled and advocates for private care sparred Monday in the second meeting of a new work group formed to discuss the future of the state system.

The group, created by legislation from state Sen. Steve Newman, is charged with evaluating options to keep more centers open.

Monday's work group meeting was devoted to finalizing the criteria the panel will use to evaluate the options.

The discussion gave way to lengthy debates about word choice and priorities that appeared to be fueled largely by the different outlooks by those who were pro-training center and those who were pro-community care.

About 640 people are in the system statewide. Family representatives were dubious about whether 75 beds would be enough to meet future demand and argued families aren't being informed properly of their right to choose to remain in a training center.

The 2012 settlement agreement — reached after a federal investigation found the state wasn't providing enough community-based services for people with disabilities — doesn't necessarily require shuttering any training centers.

But downsizing the system is a key component of how the state plans to pay for the expansion of community care. The money saved by closing centers would be reinvested

into state support for community-based programs.

[Read more, comment and share](#)

6. Arizona: Standoff With HUD Over Deaf Housing Community Ends

Arizona Department of Housing * January 24, 2014

Tempe, Ariz. – Ending a two-year legal standoff over the award-winning Apache ASL Trails community, the U.S. Department of Housing and Urban Development (“HUD”) today announced that it has withdrawn its Letter of Findings and closed the investigation involving Apache ASL Trails. In a letter to Director Michael Traylor of the Arizona Department of Housing, HUD concluded that Section 504 does permit Apache ASL Trails to give priority in rental to those individuals who need the accessibility features of the units.

The resolution comes with a promise from HUD that it will permit Apache ASL Trails to continue offering priority to applicants who need the unique accessibility features provided at the community.

Traylor, who has long championed the rights of deaf Arizonians to have full and equal opportunity to access the housing of their choice, applauded today’s resolution, saying, “All citizens have the right to be a vibrant part of their community, to choose where they want to live.”

[Read more, comment and share](#)

[Read related talking points in support](#)

7. Kentucky: A new wave of progress in healthcare is coming

***EP Magazine* * August 2013 * by Matt Holder, MD, MBA, Chief Executive Officer of the Lee Specialty Clinic and the President of the Academy of Developmental Medicine and Dentistry**

Excerpts

On June 11, 2014, Governor Steven L. Beshear presided over the ribbon cutting ceremony for the Lee Specialty Clinic in Louisville, Kentucky. While this ceremony celebrated the opening of just one clinic in one city in the United States, this single event marks one of the most significant developments in healthcare for individuals with intellectual and developmental disabilities in decades.

The Lee Specialty Clinic focuses exclusively on people with intellectual and developmental disabilities. Its core services include primary care medical services, specialty medical services, dental services, psychiatric and behavioral services, physical therapy, occupational therapy, speech therapy, and crisis intervention services. These services are provided in an interdisciplinary fashion, whereby the professionals who provide them communicate with each other for the benefit of the patient. The Lee Specialty Clinic also serves as a teaching and research program where students from any healthcare discipline can learn, intensively, how to care for people with I/DD. Finally, and perhaps most important of all, the clinic model is reproducible. Its funding model has been approved at the federal level and its coordinated through the Medicaid system. This means that any state that desires to create such a model can do so.

YEARS OF COLLABORATION

The creation of the Lee Specialty Clinic did not occur overnight. In fact, it took years of collaboration

between doctors, families, advocates, self-advocates, policy makers and governmental professionals, but its existence stands as a testament to what can be achieved when all of these groups work together for the benefit of people with IDD.

The origin of the Lee Specialty Clinic dates back to 1999 when a dentist, Dr. Henry Hood, a family advocate, Louise Underwood and a state legislator, Representative Jimmie Lee worked diligently to create a pilot dental program. After three years of advocacy, the Underwood and Lee Dental Clinic opened its doors to the public in 2002. At the time, it was estimated that the clinic might serve two or three hundred people with IDD from the Louisville metropolitan area. By 2006, the clinic had received multiple awards for its innovative approach and quality outcomes and it was serving around 700 patients from over 30 counties in Kentucky. Some families drove five hours across the state just to come to the clinic.

[Read more, comment and share](#)

8. Ohio: State officials, advocates to meet

The Columbus Dispatch * August 2, 2014

The director of the Ohio Department of Developmental Disabilities says he and other state officials will meet with a legal-advocacy group that is accusing the state of violating the Americans With Disabilities Act.

But, John Martin told Disability Rights Ohio in a letter on Thursday, officials “do not agree with many of your findings and conclusions” about access to community-based services.

He said the department would discuss its current efforts to downsize institutions, get more people competitively employed and develop a long-term plan to set benchmarks for what the system should look like in 10 years.

Disability Rights said yesterday that those initiatives might not prevent a lawsuit.

[Read more, comment and share](#)

9. New Jersey: State must reevaluate developmental center transfers (Opinion)

***The Record* * Opinion Editorial by State Senator Bob Gordon (D-38-Fair Lawn, NJ) and Senator Peter Barnes III (D-18-Middlesex, NJ)**

The forced closings of the North Jersey and Woodbridge Developmental Centers and the Christie administration's "Return Home New Jersey" initiative are causing extreme upheaval and uncertainty for many families. It's time for the administration to reevaluate its approach and embrace several common-sense measures that preserve adequate care for developmentally disabled residents, while demonstrating some necessary compassion to their families.

[Read more, comment and share](#)

10. New York: Exclusive update - Sex offenders in group homes

WHEC News 10 (NBC) (Rochester, NY) * July 31, 2014

Convicted sex offenders moved quickly into neighborhood group homes. A dozen sex offenders had been staying at the Monroe Developmental Center in Brighton until the state closed it down. News10NBC tracked seven of those sex offenders to two group homes in West Seneca with families living on the same street. News10NBC is learning how many times police have been called to those group homes since the sex offenders moved in.

[Read, comment and share](#)

11. Nebraska: Cops increasingly the first call for mental health episodes

Lincoln Star Journal * November 10, 2013

Mental health calls fielded by Lincoln police each year almost doubled from 2001 to 2012.

The number — not including suicides or attempts — grew steadily from 1,276 in 2001 to 2,294 last year, an overall increase of 80 percent, according to Lincoln Public Safety Director Tom Casady.

When factoring in the city's 15 percent population growth — about 35,000 more people — during that time, the adjusted increase works out to 56 percent.

“The increase in these cases during the past dozen years has been dramatic — even when population growth has been taken into account,” Casady said in a recent post on his blog, The Director’s Desk.

[Read more, comment and share](#)

FEDERAL NEWS

12. Achieving a Better Life Experience Act Act Clears House Ways and Means Committee

The Arc Capitol Insider * August 4, 2014

The House Ways and Means Committee marked up the Achieving a Better Life Experience Act (ABLE) last week.

The bill has significant bi-partisan support in the House and Senate and the lead sponsors are hopeful it can clear Congress in the early fall.

The ABLE Act would create tax-favored savings accounts for people with disabilities that

would not count toward the \$2,000 individual asset limits that apply to the Supplemental Security Income (SSI) and Medicaid programs. To address cost concerns, the scope of the bill was significantly narrowed from the legislation that was introduced in 2013. Among the changes are a cap on contributions at \$14,000 a year; requiring that individuals open accounts in their home state or with a state which contracts with their home state; limiting individuals to only one ABLE account; and limiting the availability of ABLE accounts to people who acquire the disability before age 26.

The Joint Committee on Taxation (JCT) estimated the new bill to cost about \$2 billion over 10 years and a new estimate by the Congressional Budget Office is expected soon. During the mark-up, Chairman Camp (R-MI) and Ranking Member Levin (D-MI) discussed their commitment to work over the August recess to find “pay-fors” acceptable to both sides in order to allow the bill to move quickly following Labor Day.

13. Autism/Health – Senate Passes Autism CARES Act

The Arc Capitol Insider * August 4, 2014

Late on July 31, the Senate unanimously passed “Autism Collaboration, Accountability, Research, Education, and Support Act of 2014” or the “Autism CARES Act” (S. 2449), sponsored by Senators Robert Menendez (D-NJ) and Mike Enzi (R-WY) and Representatives Chris Smith (R-NJ) and Mike Doyle (D-PA) . The bill reauthorizes the Combating Autism Reauthorization Act of 2011 for an additional five years. Since its original enactment in 2006, the law has advanced the science and practice in the autism field by increasing the number, scope, pace, and coordination of research, surveillance, public

awareness, and professional training efforts. The new measure will continue these efforts and includes a number of welcome changes: a name change that uses more respectful language, a designated ASD position in the Department of Health and Human Services to oversee the law's implementation, increased representation of self-advocates and family members on the Interagency Autism Coordinating Committee (IACC), and requiring a report on the needs of transitioning youth.

14. Convention on the Rights of Persons with Disabilities Passes Senate Committee

The Arc Capitol Insider * August 4, 2014

The Senate Foreign Relations Committee passed the UN Convention on the Rights of Persons with Disabilities (CRPD) out of committee with a vote of 12-6. Proponents are hopeful that it will be put to a floor vote in the Senate this week, prior to the August recess.

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Calendar Reminders:

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 information and the schedule can be found [here](#).

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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