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August 30, 2013



Speaking out for people with intellectual & developmental disabilities



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VOR Weekly News Update

News and views for VOR Advocates

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VOR and You

1. Your help needed: VOR seeks to develop a list of trusted estate planning and guardianship attorneys

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Reminders:
Help VOR Grow!

If you have worked with an outstanding estate planning and guardianship attorney, we'd like to hear from you!

Please send the name(s) and contact information of those attorneys you have successfully worked with in securing and updating guardianship, help with special needs trusts, and other life planning needs for your family members with developmental disabilities.

Once compiled, we'll use this list to provide referrals to other VOR members and families seeking legal counsel.

You can send your referrals to:

Tamie Hopp

VOR Director of Government Relations & Advocacy

thopp@vor.net

Disclaimer

VOR understands that upon sharing the names of attorney(s) that you have worked with that you are not also guaranteeing ultimate success and satisfaction for other prospective clients. Likewise, VOR makes no such guarantee. The decision to retain an attorney and terms of any attorney/client relationship are between the attorney and prospective client.

2. VOR's Executive Director says "thanks" in a letter to the editor

***Verona-Cedar Grove Times* * by Julie Huso, VOR Executive Director * Submitted on August 26, 2013**

It's rare these days when families of individuals with profound developmental disabilities who receive facility-based care can write to the media to simply say, "thank you." Too often, stories detailing the proposed closures of their adult family members' homes neglect entirely the opinion of families.

Yet, an [opinion editorial in the Verona-Cedar Grove Times](#), which encourages opposition to the closure of two developmental center homes, embraced the families' wisdom and expertise: "And those who are speaking out on their behalf, mostly family members, most certainly understand the

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challenges faced by their relatives more than a state official or task force member making these recommendations” (Verona-Cedar Grove Editorial: Seeking support for those in need, August 19, 2013).

Thank you. We couldn't have said it better ourselves.

We hope the Cedar Grove Council follows suit and, as the families have requested, strongly opposes the closure their loved ones' homes. Cedar Grove would be in good company with several other Townships and hundreds of families across the state who also oppose closure. As Margaret Meade once said, "Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has."

[Read “Seeking support for those in need,”
comment and share](#)

3. VOR Board Member, Mary Vitale, speaks out in St. Louis Times Today Letter to the Editor

St. Louis Times Dispatch * by Mary Vitale, VOR Board Member * August 24, 2013

Background: Governor Jay Nixon has vetoed Missouri House Bill (HB) 253 which would impose a tax cut that would lessen the budget of our Department of Mental Health. Families support the veto, for reasons explained in Mary Vitale's letter to the editor (below). The legislature is set to vote to sustain or override the veto on September 11.

Letter to the Editor

By Mary Vitale

August 24, 2013

The "Grow Missouri" television commercials currently being aired are in support of HB253 which reduces taxes. The happy faces seen in these ads are misleading and deceiving. In truth, if HB253 becomes law, the real faces of the effects of HB253 will be ones of despair.

According to an impact study from the Department of Mental Health, extreme cuts would be made including services for persons with intellectual and developmental disabilities. Rates for providers of developmental disability services in the community would be decreased, causing some of them to go out of business. This would mean closure of homes and

displacement of current residents. Habilitation center homes would be decreased from several centers across the state to two in the St. Louis area. The number of residents in the habilitation centers would be decreased. This would mean an increased need for community services while community providers are financially forced to close!

Residents currently living in habilitation centers are persons with severe intellectual disabilities, multiple physical impairment, extreme behaviors, and ongoing medical concerns. The services received in habilitation centers are critical to their safety, health, and daily living environment. HB253 will put them at a high risk for neglect, abuse, and death.

Governor Jay Nixon has vetoed HB253. Legislators will vote in September to override the veto, or keep the veto. They should keep the veto of HB253 so that Missouri citizens in most need of help can keep their lifesaving services.

Health News

4. Registered Dental Assistant and Mom offers tips for working with patients with special needs

DrBicuspid.com * August 22, 2013

SAN FRANCISCO - As a dental assistant, Niki Henson, RDA, was confident that she would be able to schedule a dental appointment for her two sons who both have special needs.

But she was shocked at the responses she got. "I was turned away from dental offices where I knew the dentist," Henson, president of Cornerstone Academy in Cypress Texas and a member of the American Dental Assistants Association (ADAA) who has served on the ADAA's Council on Education, said during a presentation August 17 at the California Dental Association's (CDA) fall meeting.

Her son Dustyn, 17, has been diagnosed with spastic triplegic cerebral palsy and has an intellectual disability as well, Henson explained. Caleb, 12, has had chronic ear infections in the form of a recurring

and invasive cholesteatoma that has come within 1 mm of entering his brain's membrane multiple times. He has had 20 surgeries to date with at least one more planned when the infection is controlled enough to allow it, she noted.

Hurt and confused by the responses she received from so many dental practices, Henson reached out to two parents' networks, the Parent to Parent Alliance and Family 2 Family. She wanted to see if other parents had similar difficulty in scheduling dentist appointments.

"I thought I'd get a few responses," Henson said. "I got over 5,000 within a couple of weeks. The need is so great and the workers are so few."

During her CDA presentation, Henson discussed how hygienists, assistants, and dentists can work with children with special needs and their parents in ways that are sensitive to their situation and cost-effective. Her approach was distinctively personal as she showed the audience pictures of her two kids.

[Read more, comment and share \(free registration may be required\)](#)

5. New resource: Children with Special Healthcare Needs and the Affordable Care Act

The Genetic Alliance * August 29, 2013

Approximately one of every seven children under 18 years of age, or 14 percent of children in the United States, has a special healthcare need. Children with special healthcare needs require healthcare coverage that is universal and continuous, adequate and affordable. Gaps in healthcare coverage can cause significant problems for CYSHCN in accessing care and financial hardship for their families.

How will the Affordable Care Act (ACA), signed into law March 2010, affect coverage for children with special healthcare needs? The Catalvst Center <http://hdwa.org/catalvst/> has

created a side-by-side comparison of major provisions and the implications for children and youth with special healthcare needs <http://hdwg.org/sites/default/files/ACAsidebyside-catalystctr.pdf> to help describe how coverage and care will be impacted. The Center has also developed several presentations and fact sheets about the Affordable Care Act.

Worth Repeating!

6. Reminder [Have you taken action? Calling for DD Act Investigation, Reform and Reauthorization has never been easier AND NECESSARY!](#)

Quotables

“There comes a time when one must take a position that is neither safe, nor politic, nor popular, but he must take it because conscience tells him it is right.” — Martin Luther King, Jr., A Testament of Hope: The Essential Writings and Speeches

"And those who are speaking out on their behalf, mostly family members, most certainly understand the challenges faced by their relatives more than a state official or task force member making these recommendations" ([Verona-Cedar Grove Editorial: Seeking support for those in need](#), August 19, 2013).

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Calendar Reminders:

***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.

*** AHCA/NCAL to host Intellectual and Developmental Disabilities (ID/DD) Day – October 6, 2013. [Details online.](#)**

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