



Speaking out for people
with intellectual disabilities

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VOR Weekly E-Mail Update

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VOR and You

1. The Voice * Winter Edition – corrections

The VOR winter edition of *The Voice*, VOR's print newsletter, has arrived!

Members received their newsletter within the last week or so. We hope you enjoy this edition which introduces you to VOR's co-Presidents, Sybil Finken and Ann Knighton, as well as stories from siblings Carly Engels, Maureen Durken, Anne Pichette, and Mary Durkan.

With apologies, we share here two corrections:

First, on page 4 of the newsletter, Marlo Engels' name is misspelled in the picture caption featuring Marlo, Carly and Jordy. Apologies Marlo!

Second, the link to State News (page 10) is broken. [For State News click here.](#)

2. Coming Up: Action Alert and Course 3 * Stephanie

Vance

Next week, VOR will disseminate **Course 3** from Stephanie Vance on effective legislative advocacy training course. This advocacy training is free to VOR members.

Also next week, a **VOR Action Alert** will be disseminated. Friday, December 16 marks the target adjournment date for Congress. Members of Congress will be working for the district and state offices throughout December and into early January. This presents an excellent opportunity for you to meet directly with your U.S. Representative to seek his support for H.R. 2032, including his/her support for Judiciary Committee action. Full details will be provided in the upcoming Action Alert; however, you encouraged to request a meeting with your U.S. Representative as soon as possible. To locate district office contact information visit www.congress.org and enter your zip code. Thank you!

3. A Picture is worth a thousand words

VOR affiliate, DSI Supporters (Florida) has published some [compelling pictures and related stories](#) on its website. Pictures and personal stories are a very effective way to convey the urgencies of our issues to elected officials.

Similar stories are also available on [VOR's website](#). If you would like to submit your story for consideration, please send your stories and pictures to thopp@vor.net. Thank you!

Federal News

4. Disability Programs In Limbo Following Supercommittee Collapse

Disability Scoop * November 28, 2011

The collapse of Congress' supercommittee last week could lead to mandatory cuts among several federal programs benefiting people with disabilities, advocates say.

Last week, Democrats and Republicans on the so-called "supercommittee" said that they were unable to reach an agreement. The panel of a dozen lawmakers was tasked with developing a plan to reduce the nation's deficit ahead

of a Nov. 23 deadline.

Without a deal, automatic spending cuts to the tune of \$1.2 trillion were triggered and are slated to begin in January 2013.

And that leaves several unknowns for the disability community, advocates say. While programs like Medicaid and Social Security will not be affected, other government programs assisting people who have disabilities with everything from housing to transportation to employment could be in jeopardy. [Read more.](#)

5. Disability Groups Urge Feds To Decide On Community Living

Disability Scoop * November 29, 2011

Months after the end of a public comment period, dozens of disability advocacy groups are pressuring Medicaid to make a final decision on new rules that would define what qualifies as community-based housing.

In a joint letter sent last week to officials at the Centers for Medicare and Medicaid Services, nearly 100 advocacy groups asked the government agency to “move swiftly” on a proposed regulation that would limit the types of qualifying residences under Medicaid home and community-based services waivers.

Medicaid officials say the proposed rules were prompted after they heard reports of homes built on the sites of former institutions that were being labeled “community-based.”

Nonetheless, the proposed rules are not without opposition. Among the hundreds of public comments submitted to Medicaid were those from parents who believe that their children would be best served by living in a community of their peers with disabilities. ([Read VOR's comment here](#))

Medicaid officials say they have no specific timetable for issuing a final regulation. [Read more.](#)

Reaching the Media

6. Massachusetts: A far cry from ills of years ago, Fernald of today serves vital need

Boston Globe * November 29, 2011 * Letter to the Editor by David Kassel, COFAR

(See related blog, [Globe Tells Half the Story about](#)

[Fernald](#)).

Yvonne Abraham's Nov. 24 column about four men who left what was then known as the Fernald School 40 years ago ("Celebrating the gift of being free," Page A1) describes the lives of these men with sensitivity. Unfortunately, it perpetuates misconceptions about the Fernald Developmental Center that exists today.

Abraham fails to mention the dramatic improvements that were made after the federal court assumed oversight in the 1970s of care delivered in Massachusetts to people with intellectual disabilities. Moreover, Abraham implies that, because the four men she interviewed are better off living in the community today than they were at Fernald in the 1950s through the 1970s, that means all Fernald residents today would be better off in the community as well.

She writes, "The goal now is to keep people with disabilities in the community, to help them realize their potential." However, the US Supreme Court, in *Olmstead v. L.C.*, recognized that for some people with the most severe and profound levels of intellectual disability, institutions such as Fernald may well provide the most appropriate care.

The untold story here is that Fernald and the five other remaining developmental centers in Massachusetts today are state-of-the-art facilities that serve a population that needs their high level of services.

7. Kentucky: State also needs transparency in care of the disabled

Herald-Leader * November 27, 2011 * Letter to the Editor by Don Putnam

The Herald-Leader's Nov. 13 editorial calling for Gov. Steve Beshear to open the books on the death of children is commendable. However, it leaves one key question unanswered. Why limit the editorial call for a Cabinet for Health and Family Services system overhaul to a chronological age specific group — children?

The same cabinet system weaknesses and secrecy are evident in their care for the nursing home elderly, and for Kentucky citizens with intellectual or developmental disabilities that live in cabinet-provided community-based residential settings.

Many individuals with a severe or profound level of intellectual disability are chronological adults who function as a toddler, barely aware of dangers, non-verbal, some unable to hear or see, unable to call for help, unable to say "he or she hit me". When they die, often unusually and untimely, there are virtually no records available to help us understand why and how they died.

Last year, the Council on Developmental Disabilities in Louisville sponsored a 15-member [Task Force on Protection and Transparency](#). Task force members believe strongly that the governor must support a culture of transparency within state government (and intellectual and developmental disability programs in particular) and assure constituents that his leadership team is implementing policies and practices that reflect a culture of transparency. [Related story here.](#)

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