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December 20, 2013



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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**Wishing all choice advocates a joyous and safe holiday season. Happy New Year! ~ From the VOR Board of Directors and Staff.**

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### **VOR and You**

#### **1. Two views: VOR responds to New Jersey DD Council's letter asking "Whose Choice and Where's the Diversity?"**

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In its October 2013 issue, *EP Magazine* published "[When Equitable Does Not Mean Equal: Respecting Diversity and Choice: VOR presents its Key Principles in Support of Ensuring the Rights and Opportunities for All People with Disabilities](#)," VOR's perspective on individual choice and diversity of needs. The article included VOR's "Key Principles in Support of Ensuring the Rights and Opportunities for All People With Disabilities" and VOR's request to the broader community of advocates to support these person-centered principles.

In response, Alison Lozano, the Executive Director of the New Jersey DD Council, wrote a letter criticizing VOR's choice position and article, arguing instead that "Everyone [with developmental disabilities] must live alongside everyone else in a regular neighborhood, enjoying their community to their fullest extent. This is what is called diversity."

Alongside her letter, *EP Magazine* also published VOR's rebuttal to Dr. Lozano's claim.

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Geoffrey Dubrowsky, a VOR Officer and New Jersey DD Council Member, corrected her characterization of VOR and explained VOR's position in support a full array of residential options, from small homes to larger licensed facility based care, based on individual need and choice. His positions in both VOR and the New Jersey DD Council, and his role as an advocate for his son (who lives at home), his nephew who lives at home and will need community-based services in the future, and his niece who receives facility-based care, lent credibility to his (and VOR's) position in support of legitimate choice based on individual need.

[To read both letters, click here](#)

[To read VOR's original article and principles, click here](#)

**2. From Delaware: Great Testimony in Support of "The Right Care at the Right Time in the Right Place"**

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[Testimony before the Delaware Legislature's Joint Finance Committee \(Feb. 21, 2013\) \\* Micki Edelsohn for Families Speaking Up](#)

**Editor's note:** VOR has been working closely with Micki/Families Speaking Up in a coalition of organizations concerned about proposed CMS regulations that will so narrowly define "community" that current and future innovative housing solutions will be closed from lack of funding or never be built. To speak out, sign [this petition](#) and read related articles in [VOR's Weekly E-News Update](#), December 13, 2013).

**"The Right Care at the Right Time in the Right Place"**

"My name is Micki Edelsohn. Some of you know me for the many roles that I have taken in

the disability community in the State of Delaware. Today I represent Families Speaking Up a non-partisan, grass roots group of families advocating for people with intellectual and developmental disabilities who are concerned about the future of our family members

“My journey into the world of disabilities began over 40 years ago with the difficult birth of my son Robert. As a mother I have learned a great deal during these past 40 years . . .

“In 2011, President Obama appointed me to the President’s Committee for People with Intellectual Disabilities. This has given me the opportunity to see how things are trending at both a national and state level, and I must tell you I am deeply concerned about the direction of the disability movement. . .

“Unfortunately many, even in the disability community, are now using these laws and definitions and advocating for changes without considering “capacity”. They are gravitating towards a “one size fits all” approach for a population that is most vulnerable. The reality is that the intellectual capacity of those I advocate and care for range from those who have severe limitations to those who thrive in competitive employment, drive a car, may marry and, very appropriately, self advocate. One size does not fit this diverse population.

“Secretary Landgraf has framed it perfectly – the Right Care at the Right Time in the Right Place . . .”

[Read more, comment and share](#)

### **State News**

**3. Tennessee: Change Is The Only Constant - One family's story of swapping unavoidable change for opportunity, to the benefit of their daughter with developmental disabilities and**

her peers

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***EP Magazine \* December 2013 \* By Ralph Kennedy***

***About the author: Ralph M. Kennedy is Marla's Dad and the Executive Director of Tennessee Family Solutions.***

As the founders of a non-profit agency serving adults with severe intellectual and multiple other disabilities, my wife, Tracy, and I realize just how much a few determined people can help make change happen for our loved ones, and how important it is to realize the generosity of this great nation and its citizens in every state in the union.

### **How Marla Changed Our World**

Marla Jane Kennedy (Tracy was told that her name means "bittersweet gift of God") is the youngest of the three girls that Tracy and I raised and, in Marla's case, are still raising. Born in 1976, at birth, Marla gave every indication of being another perfect angel. But, at four months of age, the seizures began. We have never found a definitive answer for their onset or their continuation for 37 years. At first, keeping Marla at home was our only consideration.

But soon, these troubling circumstances required us to realistically consider the survival of our family unit, and getting Marla the educational benefits our little family community tried, but failed, to deliver.

Over the years Marla was served in multiple of community settings, including group homes and foster care. It was a very mixed bag and it seemed we were always begging good staff to stay, and advocating to have the not so good staff removed.

At one point, Marla was found wandering along a four-lane highway while her staff

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allegedly took a one-and-a-half hour shower.

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#### **4. Wyoming Department of Health Issues Final Report on Wyoming Life Resource Center Study: Concludes Center is Necessary Safety Net and Should Not Be Closed**

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**Wyoming Department of Health \* November 1, 2013**

After an 8 month legislatively-directed study, the Wyoming Department of Health (WDH) concluded that the residents of the Wyoming Life Resource Center (WLRC) should not be forced to transfer to smaller programs. "The WDH considers the WLRC to function as a safety net in Wyoming. While there are many reasons for this recommendation, perhaps one of the most basic (yet critical) reason is the fact that a majority of the current WLRC clients have resided at the facility for the majority of their lives. A transition could impact their physical and mental well-being, resulting in a decline in their current conditions," the report concluded.

Lawmakers earlier this year asked the health department to study the most effective way to care for the center's residents. Most of the people living at the Lander facility have severe developmental disabilities or acquired brain injuries that require intensive support. Many also exhibit severe behavioral problems.

In addition to resident well-being, community capacity and family/guardian perception of individual quality of life at WLRC factored into WDH's conclusions. "In summary, guardians/family members of WLRC clients that chose to respond to this survey indicated they (and their clients) are very satisfied with the services at the WLRC. Some also stated that in previous placements outside WLRC. they and

their wards were unsatisfied with the arrangement.

Finally, the perception reported by the majority of the guardians/family members was that their clients would not experience as high a quality of life as they do at WLRC if they transitioned to a community setting.

Family members surveyed for the study said moving their loved ones to community programs would result in a lower quality of life.

[Read more and share](#)

## **5. California: Advocates for Residential Choice Speak on Draft Developmental Center Task Force Report**

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**California Association of Psychiatric Technicians (December 20, 2013)** - A Lanterman Developmental Center (LDC) Psych Tech serving on the state Task Force on the Future of Developmental Centers strongly cautions that much more needs to be done prior to taking any action of any kind regarding California developmental-center services. In a letter to task-force leader and California Health and Human Services Secretary Diana Dooley regarding the group's draft report to the Legislature, Brad Whitehead noted that, while the draft document isn't a closure mandate and offers hope for continuing and reimagining state developmental services, in-depth data- and choice-driven work remains. "I maintain the heartfelt hope that our task force has not been a mere formality, but that it actually marks the start of what must be a much more involved statewide and national conversation on the need for quality, professional services for all Americans with developmental disabilities."

Kathleen Miller, President of the Parent Hospital Association, who served on the Task Force, also sent a letter to [Secretary Dooley](#) stating that information on outcomes associated with prior transitions from developmental center care to smaller settings was critical before making any determination about the future of California's developmental centers. "Until

death data confirming that these services, and the transitions to them, do not cause the decline and unintended deaths of medically fragile developmental center clients, they should not be forced into other living options. Currently we do not have access to this data," she wrote. "Before we eliminate the safety net of the Developmental Centers for those with enduring and complex medical needs, we request that there be data collected on death rates. In the event that there is an increase in the rate of deaths during closures; we feel that needs to be addressed prior to any plan to move the remaining medically fragile individuals out. It is only reasonable that the DDS and anyone concerned about the safety and well being of these individuals would do this."

[Read Brad Whitehead's letter here.](#)

[Read Kathleen Miller's letter here.](#)

**6. Massachusetts Petition: Allow Sara Duzan to return to her family from a group home for the intellectually disabled, which is refusing to allow any contact between her and her family**

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**COFAR Petition on Change.org \* December 2013**

Sara Duzan's mother and father, Maryann and Paul, lost their guardianship of Sara in 2009, based on an admission by Maryann that she once slapped her daughter on the cheek, and the apparent perception that the family has been too aggressive in advocating for her.

As a result, a series of increasingly restrictive limits has been placed by court-appointed guardians and residential providers on family communication with Sara. Since June, the family has not been allowed to see Sara, who is currently living in a group residence in Westminister, MA, run by a state-funded, corporate provider.

[Learn more and sign petition](#)

[Read related blog](#)

## Research News

### **7. Annual Compendium of Disability Statistics**

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**Andrew J. Houtenville, Ph.D. \* University of New Hampshire, Institute on Disability**

On Wednesday December 11, 2013 the [Annual Compendium of Disability Statistics](#) was released.

The Annual Disability Statistics Compendium is a publication of statistics about people with disabilities and the government programs which serve them. It is modeled after the U.S. Department of Commerce's annual Statistical Abstracts of the United States. The Compendium is designed to serve as a reference guide to government publications. At the bottom of each table, the source of data appearing in each table is presented. These referenced sources contain additional statistical information about the ways the data were collected and the statistics were generated. Each year, the Compendium reflects the statistics published over the year.

#### **Quotables**

*"This is not the end, this is not even the beginning of the end, this is just perhaps the end of the beginning."* ~ by Winston Churchill, as provided by Families Speaking Up

*"Just as one size cannot fit all, one perspective cannot know all, one voice does not tell all!"* ~ Micki Edelson, [Families Speaking Up](#)

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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](mailto: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. [Details coming soon](#)

**Week of June 9, 2013**

**VOR 2014 Congressional Initiative:** Families and advocates visit Capitol Hill. [Details coming soon](#)

**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**

**\*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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