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July 18, 2014



Speaking out for people with intellectual & developmental disabilities



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VOR and YOU

1. **A Tribute to Mary McTernan**, Retiring Board Member, Long-Time Advocate

**Make a Lasting
Impact with a
Will Bequest**

**Reminders:
Help VOR Grow!**

[A special thanks to VOR member George Mavridis who helped write this tribute].

On June 30, 2014, Mary McTernan, VOR Past President, long-time Officer and Board Member, Committee Chair, member and donor, ended her final term on the VOR Board of Directors.

Mary has contributed so much for so long to VOR, never seeking or wanting credit or attention for her many contributions. Her departure in this official role on our behalf provides a fitting opportunity to offer a well-deserved tribute.

Mary's foray into advocacy on behalf of people with intellectual and developmental disabilities (I/DD) began like most of VOR members – the birth of her daughter, Mary Elizabeth. Being the mother of a daughter with I/DD whose cognitive level is about eighteen months lead to being president of the Hogan Regional Center's family association and holding various positions (including President) in the Massachusetts Coalition of Families and Advocates (COFAR).

It was her involvement in COFAR that led her to 22-year (and counting) history with VOR.

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2. From VOR: People as Pendulums: Deinstitutionalization and People with Intellectual and Developmental Disabilities

***The Nonprofit Quarterly* * July 16, 2014 * By Tamie Hopp, VOR**

Excerpts

[\[Read full article here\]](#)

Early reforms were quite properly motivated by the need for a system of care and supports that responded to the very individualized and diverse needs of the entire population of people with I/DD. These reforms, however, also set the stage for decades of ongoing deinstitutionalization, resulting in the elimination of specialized housing, employment and education options for people with I/DD, leaving some to question the price of "progress."

The Pendulum Swings

Even though initial reforms were motivated by a lack of service options (an over-reliance on the ICF/IID program), it was not long before efforts to "rebalance" our system of care shifted from the expansion of options to the dramatic reduction of ICFs/IID and other specialized options.

In 1999, the Supreme Court handed down its landmark *Olmstead v. L.C.* decision, which should have settled the deinstitutionalization debate. The Court expressly cautioned against forced deinstitutionalization, the "termination of institutional settings for persons unable to handle or benefit from community settings,"^[iii] finding instead that the Americans with Disabilities Act (ADA) only requires community placement when an individual's treatment professionals determine community placement is appropriate, such placement is not opposed by the individual, and the

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placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with disabilities

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STATE NEWS

3. VOR's Annual State Report Forum: Reports now online

Reports from the June 7, 2014 Annual VOR State Report Forum are available at vor.net/events.

4. Massachusetts: Sheltered workshops for the disabled win big reprieve

COFAR Blog * July 7, 2014

A major effort by Massachusetts advocates of employment choice, including sheltered workshops, to persuade state legislators and Governor Deval Patrick that the workshops provide invaluable skills and activities for their loved ones with intellectual disabilities has paid off. Language in the State's Fiscal Year 2015 budget, signed by the Governor, says that the state must not "reduce the availability or decrease funding for sheltered workshops serving persons with disabilities who voluntarily seek or wish to retain such employment services." Passage of this language appears likely to cause at least a slowdown in the administration's plans to close all remaining sheltered workshops as early as next June.

[Read more, comment and share](#)

5. New York: Guest Viewpoint - Issue of disabled wage is complicated

Press & Sun-Bulletin * July 17, 2014 by Marc Brandt is the executive director of NYSARC (The Arc of New York State)

The Press & Sun-Bulletin paints a very complex situation with a brush that is far too broad ("[Beneath the minimum](#)," June 29).

NYSARC does agree that the subminimum wage and sheltered employment can be inappropriately used. Many NYSARC chapters have significantly or completely eliminated sheltered employment. Others are striving to follow suit, and NYSARC advocates continually for the jobs and government funded supports necessary to accomplish that goal.

For now, though, the subminimum wage and sheltered employment often separate people with developmental disabilities from meaningless lives of prolonged inactivity and deteriorating functional capabilities. Sitting at home doing nothing for 24 hour a day is bad for the most able of us. For people with disabilities, it is a personal catastrophe. During a period in which employment remains elusive for the most able workers, it can be impossible for many people with disabilities.

[Read more, comment and share](#)

6. New Jersey: In Debate Over Residential Choice, Residents Rarely Heard

Make a Lasting Impact with a Will Bequest

Disability Scoop * July 16, 2014

In spite of her severe cerebral palsy, Wendy English can make her own legal, medical and financial decisions, vote in local and national elections, and communicate with the help of a specially programmed iPad. But she can't control the thing she deems most important to her life: the decision to remain in her longtime home.

English, 51, is one of about 1,000 people with developmental disabilities New Jersey is moving from its state operated facilities (ICFs/IID). English doesn't want to move from the Woodbridge Developmental Center, her home for the past 18 years.

Though haltingly delivered, her words offer a rare personal insight in a debate that has been dominated by state officials, advocacy groups, and caretakers who say they know what's best for New Jersey's 40,000 people with developmental disabilities who depend on the state and federal government for their daily care. The debate seldom includes the voices of people with disabilities themselves.

English had a tumultuous early life, moving 17 times before she was placed at Woodbridge, when she was 33. Her memories of most of those places are grim. Her caregivers often tied her down. She refused to eat. A psychiatric hospital where she spent several years often neglected to bathe her.

"I'm so sorry this closure is happening to her and turning her life upside down after 18 years," said Joanne St. Amand, the president of the Woodbridge Developmental Center Parents Association [and VOR Board Member]. She has become one of English's closest friends and staunchest advocates. "The anxiety for Wendy of not knowing what was going to happen was unbearable for her."

[Read more, comment and share](#)

Watch video: [Moving Wendy: Developmental Center's impending closure causes hardship for longtime resident forced to relocate](#)

7. Illinois: State looks to argue appellate ruling on Murray wards

WILY/WRXX News (Mount Vernon,IL) * July 14, 2014

In April the Fifth Appellate Court in Mt. Vernon handed down a loss to the Illinois Attorney General (AG) when the court reaffirmed in its entirety an earlier ruling in Clinton County court appointing attorney Stewart Freeman as guardian for all state wards of Murray Developmental Center, rejecting the AG's claim that Clinton County has no jurisdiction.

In the motion for review, Illinois AG Lisa Madigan is arguing that the appellate court made a mistake in allowing the Clinton County court to rule over 24 ongoing probate proceedings, when they are pending before judges in 12 other counties across the state.

Now the AG is arguing that the appellate court's decision authorizes multiple courts of the state to accept jurisdiction over the same matter and enter contradictory orders. It claims the potential for disruption and confusion in the conduct of legal proceedings created by the court's decision is immense.

[Read more, comment and share](#)

8. Maryland: Group home for disabled children struggled to provide adequate care

The Baltimore Sun * July 12, 2014

The recent death of a 10-year-old disabled foster child at an Anne Arundel County group home was just the latest in a series of problems at LifeLine, the state contractor that has been paid millions in taxpayer funds to care for "medically fragile" individuals, a two-month investigation by The Baltimore Sun has found.

Even before Damaud Martin's death on July 2, LifeLine had struggled for years to provide around-the-clock care for its residents — adults and foster children often confined to a bed or wheelchair by paralysis, cerebral palsy and other disabilities. Its founder, Randall Martin Jr., is imprisoned for felony arson, the state disciplined the company for inadequate care after the death of three adult residents, and it is burdened by tax liens and other debts.

Maryland regulators were unaware of many of LifeLine's problems, including police reports alleging neglect, The Sun's investigation showed — raising concerns about state oversight of these group homes. The state has awarded LifeLine \$18 million in contracts since 2010 to care for children, despite reports that warned of financial difficulties and inspections that highlighted shortcomings in care.

And it wasn't until July 3 — a day after Damaud died and weeks after the company was warned it would lose its license — that the state finished moving the last children from LifeLine's care.

[Read more, comment and share](#)

9. Family Caregivers of Adults With Intellectual and Developmental Disabilities: Outcomes Associated With United States Services and Supports

An [article](#) in the April issue of Intellectual and Developmental Disabilities by researchers affiliated with the University of South Florida examine how care delivery and support systems vary widely globally, and suggest that consideration of caregiver outcomes, in the US context, is needed. Authors report that understanding and responding to the changing needs of family caregivers is vital to the US disability service system to effectively prioritize formal resources and services.

For more information contact Tamie Hopp at thopp@vor.net.

FEDERAL NEWS

10. Workforce Innovation Act Passes: Workshop eligibility limited, National Council on Disability changed

Disability Scoop * July 10, 2014

The new federal law will prohibit individuals with disabilities age 24 and younger from working in jobs paying less than the federal minimum of \$7.25 per hour unless they first try vocational rehabilitation services, among other requirements. There are exceptions, for those already working in sheltered employment and in cases where individuals are deemed ineligible for vocational rehabilitation

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In addition, the new law calls for a smaller National Council on Disability (NCD) (from 15 to 9 members) and a new appointment process that takes sole discretion away from the President and includes Congressionally-appointed membership. The first of the changes will take effect in September 2014, upon the expiration of terms of 4 current Council members.

VOR has been critical of NCD and its bias against individual choice in housing and employment options for people with intellectual and developmental disabilities.

Quotable

"A good man fights for himself and a great man fights for everyone else."
- Philip De Franco

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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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