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VOR

Speaking out for people with intellectual disabilities

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January 6, 2012

VOR Weekly News Update

News and views for VOR advocates

E-Mail Address Change? Don't miss a single issue. Please let VOR know if your e-mail address changes.

VOR and You

1. Save the Date: VOR 2012 Annual Conference and Washington Initiative

2. Folded Napkin Follow-up

Action Center

3. Press Release / Help us spread the word: VOR Calls for Moratorium on Deinstitutionalization Lawsuits

Featured Article: Olmstead and Choice

4. LTO Ventures releases report: Choice v. Olmstead - The Medicaid debate over community living and the impact on housing for adults with autism

Coming Up:

- The Face of VOR: Meet Thomas
- Partlow closes despite family opposition
- Stephanie Vance's E-Advocacy Course #4 (members only)

VOR and You

1. Save the Date: VOR 2012 Annual Conference, Legislative Briefing and Washington Initiative

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Conference Overview * Details Coming Soon

VOR 2012 Conference, Legislative Briefing and Initiative
Expanding VOR's Horizons Through Vision and Mission
The Liaison on Capitol Hill, Washington, D.C.

Saturday, June 9, 2012

Board Meeting, State Reports, Reception

1:00 pm VOR Board Meeting; 3:30 pm State Reports; 5:30 pm Networking and Hospitality Reception.

Sunday, June 10, 2012

Annual Conference, Legislative Briefing, Dinner

1:00 pm Conference w/ speakers; 3:30 pm Legislative Briefing w/ speakers; 5:30 pm Reception w/ entertainment; 6:30 pm Dinner w/ speaker.

Week of June 11, 2012

Washington Initiative and Debriefings

Participant visits to Members of Congress and their staff. Share our choice message! Monday and Tuesday evening Initiative participant debriefings. Learn from others

2. Folded Napkin Follow-Up

Many VOR members responded positively to VOR's December 27 message, "*Something for Stevie*" - the story about Stevie, a young man with Down syndrome, his work ethic and positive attitude, as well as the generosity of the truckers whose hearts he touched. *EP Magazine* will be reprinting the story, including VOR's role in touching the lives of people with intellectual disabilities and their families. A VOR affiliate in Washington State, Advocates for People with DD, will also be sharing the story.

VOR also heard from two members who were concerned that the story, which we have learned is fictional, was not presented that way.

In response to this feedback, I reached out to the author of "*Something for Stevie*," Dan Anderson. His story was first published in *RPM4 Truckers* magazine many years ago and has since been widely distributed by e-mail. Mr. Anderson confirmed that while the specifics of the Stevie story are fictional, he was inspired by his friendship with John, a young man with Down syndrome who "impressed me with his incredible work ethic and positive, upbeat personality . . . He was the inspiration for Stevie."

This is very much VOR's story, individually and collectively. All of us in VOR are movitated by a family member or friend with intellectual disabilities to be effective and helpful advocates for *all* people with intellectual disabilities, through volunteerism and financial donations. We are their voice - and for those individuals whose intellectual disabilities will never allow them to bus tables in a restaurant or "self-advocate" - VOR (individually and collectively) is often their only voice.

As author Dan Anderson stated in my exchange with him, "*'Something For Stevie'* was an offshoot from a friendship with a young man with Downs Syndrome. It's been blessing to hear how it has traveled the world and apparently touched a lot of people."

VOR is glad to be a part of that. Although the story is fictional, the spirit of it is alive and well in VOR and its members. Indeed, that is the point of the story.

I appreciate all the feedback I received. I appreciate all of you and your support for VOR.

Sincerely,
Julie Huso
VOR Executive Director

Action Center

3. Press Release / Help us spread the word: VOR Calls for Moratorium on Deinstitutionalization Lawsuits

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***Editor's Note*:** Please share the following press release with your local media, especially if DOJ and/or P&A are active in your state. VOR has shared this information with the Virginia, Mississippi, Georgia and New York Congressional Delegations, as well as with H.R. 2032 cosponsors. In the short time since the release of VOR's "Call for a Moratorium," DOJ has issued a "findings letter" in Mississippi calling for facility downsizing; and the *New York Times* has released 2 articles, one detailing the overuse of psychotropic medications (Dec. 23) and the other exposing the resident abuse and financial malfeasance of a $20 million/year "nonprofit" group home provider (Dec. 28). A moratorium is needed, now.

VOR - Speaking out for people with intellectual disabilities
December 21, 2011
For Immediate Release
FMI: Tamie Hopp

Concerned About Deaths of Intellectually Disabled Individuals, National Organization Calls for Moratorium on Deinstitutionalization Lawsuits

VOR, a national advocacy organization representing people with intellectual disabilities and their families, today asked Members of Congress in several states to call for a moratorium of federally-funded deinstitutionalization lawsuits.

"Protection & Advocacy and Department of Justice lawsuits have forced people with severe intellectual disabilities from their specialized homes and into smaller, unlicensed settings that are too-often not prepared to handle people with such severe degrees of intellectual disability," said Tamie Hopp, VOR's Director of Government Relations & Advocacy.

VOR's call for a moratorium was prompted by the New York Times reporting of tragic preventable deaths of hundreds of people in New York group homes. Specifically, the *Times* found that "One in six of all deaths in state and privately run group homes [in New York], or more than 1,200 in the past decade, has been attributed to either unnatural or unknown causes. ("1,200 Deaths and Few Answers," November 6, 2011).

"The silence by federal agencies in response to these deaths is deafening," said Hopp. "Not only have P&A and DOJ done little if anything in response to these deaths, which numbered more than a 100 per year over 10 years, they have continued their ideological warfare on larger Medicaid-licensed and funded ICFs/MR."

Since 1996, P&A have filed at least 17 lawsuits involving ICFs/MR for the purpose of "community integration." In recent years, DOJ has also aggressively supported the closure of ICFs/MR in Georgia, Virginia, and Illinois, and is presently investigating similar facilities in Mississippi.

In Georgia, the DOJ settlement calls for the displacement of 10,000 people with mental illness and developmental disabilities. "It's a little like loading more passengers onto the Titanic," remarked William Fischer, Professor of Psychology, Center for Mental Health Services Research, University of Massachusetts.

The Independent Reviewer's first year implementation report, released October 5, cites serious problems associated with Georgia's community-based care system, including access to health care, isolation and at least one death due to neglect.

Even P&A has recently acknowledged problems with health and safety in community programs in Alabama and North Carolina (National Disability Rights Network, "Keeping the Promise: True Community Integration and the Need for Monitoring and Advocacy," December 1, 2011). In Alabama, P&A was directly responsible for the closure of facilities, leading to the very health and safety problems it now condemns.

"Remarkably, P&A asks to receive more funding so it can better investigate problems in the community," said Hopp. "VOR would rather they stop spending resources on lawsuits and other activities which serve to place these vulnerable people at risk in the first place."

VOR's call for a moratorium was sent to Members of Congress representing New York, Georgia, Virginia, and Mississippi, as well as the 66 Congressional cosponsors of H.R. 2032, federal legislation also which seeks to reform the way these lawsuits are handled.

Featured Article: Olmstead and Choice

4. Choice v. Olmstead: The Medicaid debate over community living and the impact on housing for adults with autism

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LTO Ventures * Press Release, December 14, 2011

[***VOR Editor's Note***: As you will read, VOR's concerns with regard to the proposed federal definition of "community" are consistent with LTO Ventures. In our comments to CMS (April 2011 and August 2009), "VOR urges the consideration of a definition of 'community' that is consistent with typical usage, rather than what that term has come to mean in the disability arena and reliant on irrelevant tangibles such as residence size, distancing requirements, location, and type." VOR also agrees with LTO Ventures that "Olmstead" (as a concept) has been hijacked by "community-only" disability advocates to mean something other than choice. Still, VOR recognizes *Olmstead* (the Supreme Court's Decision) to require legitimate choice.

Featured article:

Choice v. Olmstead: The Medicaid debate over community living and the impact on housing for adults with autism

HENDERSON, Nevada (Dec. 14, 2011) – A highly-emotional debate over freedom of choice versus obligations under a landmark U.S. Supreme Court ruling is dividing the disability community regarding proposed changes to a key Medicaid waiver that is the primary funding safety net for persons with disabilities including autism, according to a new report by LTO Ventures.

The "choice" versus "Olmstead" debate also has huge implications when it comes to who gets to determine what qualifies as Medicaid-eligible settings, according to report author Mark L. Olson, president and CEO of LTO Ventures and chairperson of the Community Living Subcommittee of the Nevada Commission on Autism Spectrum Disorders.

The report, released on the LTO Ventures website, examined the public comments submitted in response to the publication of the proposed new rules in the Federal Register.

Efforts by the Centers for Medicare & Medicaid Services (CMS) since 2009 to redefine under the Home and Community-Based Services (HCBS) Waiver what constitutes "community living" and "home and community-based" settings threaten to severely constrain choice and access to funding that could result in disastrous public policy that reverberates for decades. An estimated 25 percent of existing eligible residential settings would not meet the new CMS criteria, and tens of thousands of disabled individuals could be forced out of their residences.

The report found the choice side is comprised primarily of the disabled individuals served by the waiver, their parents, caregivers, providers and many state Medicaid agencies and administrators. They contend that narrowing the definition of an eligible setting would have a chilling effect on innovation in housing models and financing mechanisms, public and private, would unfairly impact the development of residences suitable for the tens of thousands of disabled adults who need them, and would balloon already bloated waiting lists nationwide.

The community at risk includes almost 123,000 disabled people on waiting lists for Medicaid-eligible residential services, an increase of almost 71% over the same waiting lists in 2000, the first year after the Supreme Court Olmstead decision. In many states, the length of time eligible individuals have languished on waiting lists exceeds ten years. And it is projected to get much worse. Data from the Centers for Disease Control and Prevention and Autism Speaks estimate that more than 500,000 individuals under 22 years of age with an Autism Spectrum Disorder will reach adulthood by 2024 and join the market for housing and services.

The report concludes that the objective of the CMS rule-making process and this debate ideally should be to produce an outcome that expands inventory and choices and removes barriers to innovation and investment in residential settings desired by adults with autism and intellectual, developmental and other disabilities. At the very least CMS must “do no new harm” and choose not to include proposed new paragraphs to the Medicaid HCBS Waiver regulation.

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