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April 25, 2014



Speaking out for people with intellectual & developmental disabilities



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**Reminders:
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VOR Weekly News Update

News and views for VOR Advocates

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VOR and You

1. Will you be our side when June 2014 arrives! **Deadlines approaching fast!**
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Register for
VOR's 2014
Conference and
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About VOR

Make a Lasting
Impact with a
Will Bequest

This is going to be a great conference with great networking and speakers. You can see [all details for our Washington, D.C. event on VOR's website](#), including dates, agenda of speakers and events, and [hotel reservation](#) information.

May 1: Annual Conference Registration Deadline (prices increases after May 1). Register [online](#) or by [mail/fax/email](#).

May 5: [Hyatt Hotel Reservation](#) Deadline to guarantee group rate and availability. All VOR events take place at the hotel.

Make your plans today. See you in June!

2. Urgent: Action Alert Expires Midnight Tonight – Tell the Senate to stop forced funding deinstitutionalization

{If the links don't work, see information directly below}

Click here for an easy "[one click](#)" way to tell the Senate to stop funding forced deinstitutionalization.

[Take action now](#). Deadline for comments is midnight (eastern)tonight, April 25, 2014. You will not be able to take action after the deadline.

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NOTE: At time of press, *SalsaLabs*, our vendor for action alerts, was having major technology issues. If [this action alert link](#) does not work, you can send the following letter direct from your e-mail to CJS@appro.senate.gov. To be considered, your email must be received today, **April 25, 2014. You are free to personalize the message, but do not change the heading (including subject line), which formatted according to [Senate Subcommittee instructions](#).**

Subject: FY15 CJS OWT

TO: Senate Subcommittee on Commerce, Justice and Science, and Related Agencies

RE: U.S. Department of Justice Appropriations

SUBMITTED BY: Citizen (full contact information directly below)

I am writing to urge the Subcommittee to PROHIBIT the use of U.S. Department of Justice appropriations to support any law or policy that limits the choices of individuals with intellectual and developmental disabilities (I/DD) (or, if an individual has a legal representative, the legal representative), seeking living arrangements they believe are most suitable to their needs and wishes, whether that be a small or large residential setting.

I believe strongly that no federal agency should define "choice" so narrowly and illegally as to disenfranchise the most vulnerable segment of our disabled population. Yet, through its "Olmstead-enforcement" actions, the Justice Department has routinely violated the letter and spirit of the Olmstead decision by evicting fragile people from their specialized, federally-licensed homes, contrary to the wishes and best interests of the affected

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individuals, and without consulting the families and legal guardians who know them best.

VOR, a national nonprofit organization advocating for high quality care and human rights for all people with I/DD, has submitted written testimony for the record with this same request. I support VOR's testimony and request.

Sincerely,

FULL NAME

FULL ADDRESS

STATE NEWS

3. National: Subminimum Wages For The Disabled: Godsend Or Exploitation?

National *Public Radio* (*All Things Considered Morning Edition*) * April 23, 2014

While some call sheltered workshops a godsend, others say they are examples of good intentions gone wrong.

With the passage of the Americans with Disabilities Act, there's been more emphasis on placing disabled workers in the mainstream labor market. Curt Decker, Executive Director for the National Disability Rights Network (P&A) and others are calling for an end to sheltered employment. They have the support of the Justice Department. Acting Assistant Attorney General Jocelyn Samuels.

The Sertoma Centre, located in Chicago's south suburbs, is one organization that provides employment opportunities to about 250 people with disabilities through subcontracting jobs such as packaging bottles for microbreweries.

Gus van den Brink says the Sertoma Centre and other agencies do work to find jobs for disabled people in the community, but the focus should not be on shutting down all sheltered workshops. He says it would be nearly impossible for some people with severe intellectual disabilities to get a job at all. It's sheltered workshops, he says, that give them a chance to work and earn a paycheck.

"Some of the individuals may not even completely understand what the value of that paycheck is," van den Brink says. "But they know they are receiving a paycheck, so they are getting a lot of self-esteem. They are very proud of it."

Even so, Assistant Attorney General Samuels says the Justice Department will work with other states to make sure some workers with disabilities have the opportunity to do their work, as she puts it, at "real jobs for real wages."

[Listen and read more, COMMENT and share](#)

4. Massachusetts: House leadership rejects politically correct view on sheltered workshops

COFAR Blog * Massachusetts Coalition of Families and Advocates, Inc., * April 18, 2014

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In a welcome counter to some political-correctness-run-amuck in the Patrick administration, the leadership of the state House of Representatives is reportedly solidly behind efforts to preserve vital sheltered workshops in Massachusetts for people with intellectual and developmental disabilities.

[Read more, comment and share](#)

5. Pennsylvania: The death no one cares about

The Philadelphia Inquirer * April 11, 2014

If Christina Sankey had been an angel-faced toddler when she went missing, we might know by now how she wound up dead, half-naked and alone, between two parked cars in West Philly on a frigid winter morning. The city would've been galvanized by her death. Government officials would've promised to find out how she met her tragic end. Someone would've created a sidewalk memorial, and others would've led prayer vigils to honor the life that was lost.

But Christina, 37, had the mentality of a 2-year-old, but not the physique. She was a 5-foot-tall, 160-pound severely autistic and intellectually disabled woman. She was well cared for by her family, but ungainly. And she would grunt in ways that are precious in babies but odd in adults.

She was also poor. Her mother, Patricia Sankey, with whom she lived, hasn't the resources nor clout to make a big deal out of her daughter's passing.

And that, I fear, is why the death of this terribly vulnerable woman-child has not even registered on the public's radar. Christina just wasn't adorable enough or from the right circumstances for her death to warrant the attention it deserves.

[Read more, comment and share](#)

6. New Jersey: The Record: Protecting the meek, Saving North Jersey developmental centers

The Record * April 20, 2014

Scripture states that the meek shall inherit the Earth. For some families in North Jersey, the meek are not so lucky. On July 1, the first of two developmental centers serving disabled individuals in northern New Jersey will close. The second is scheduled to be shut down Jan. 1. Families are scrambling, and Governor Christie has not interceded on their behalf.

[Read more, comment and share](#)

7. Massachusetts Supreme Judicial Court finds limit to abuse prevention law

The Boston Globe * April 19, 2014

The state Supreme Judicial Court Friday vacated an abuse prevention order obtained by a woman in a residential treatment

program, determining the statute does not cover people in such living situations.

“We recognize that the central issue of this case involves the serious and important matter of the safety of individuals with intellectual disabilities under state care, and respect the legitimate concerns of the victim’s guardian for the safety of her daughter,” the decision by Chief Justice Roderick Ireland stated. “Nonetheless, we conclude that the relationship between the defendant and the victim, in the circumstances here, is not the type of relationship contemplated by the statute.”

The alleged victim, Christina Silva, and the alleged aggressor, Nancy Carmel, are both intellectually disabled adults who were enrolled in a residential program at Riverside Community Care in Newton Lower Falls, funded and regulated by the Department of Developmental Services.

The restraining order forced Carmel to move away.

The Association of Developmental Disabilities Providers and the Arc of Massachusetts supported overturning the restraining order, arguing that applying the law to people in residential facilities “will . . . adversely impact persons with intellectual disabilities and the providers who serve” them.

Community Legal Aid argued that people with disabilities should have the same protections as the general public.

[Read more, comment and share](#)
[Read the *Silva v. Carmel* decision](#)

RESEARCH NEWS

8. Report: Disabled Mass. Residents Face Major Health Disparities

WBUR's CommonHealth Reform and Reality * April 22, 2014

A new [report](#) highlights the many ways in which Massachusetts residents with disabilities “fare worse” than those without disabilities when it comes to their own physical and mental health as well as access to quality medical care from doctors sensitive to their needs.

This phenomenon isn’t new. Previous research found that many barriers still exist that prevent disabled patients from accessing specialty medical care. And for those with developmental and intellectual disabilities, sometimes finding a doctor willing to treat even common medical conditions can be difficult.

The latest report, by researchers at UMass Medical School’s Disability, Health and Employment Unit working and the Health and Disability Program at the state Department of Public Health, also suggests that the state could do more to ensure that disabled patients have access to health care providers who both understand and can help with the specific medical challenges of this population.

Some Key Findings:

- Both men (7%) and women (24%) with disabilities were more likely to report lifetime sexual violence compared to men (4%)

and women (19%) without disabilities.

- Adults with disabilities (64%) were twice as likely to report being overweight as those without disabilities (34%).
- Affordable housing (77% of respondents reported this was a problem);
- Adequate dental care (64%);
- Adequate mental health services (62%);
- Finding a doctor who is sensitive to disability issues (55%);
- Transportation to doctor's appointments (54%);
- Communication supports, such as large print, Braille, Computer Assisted Realtime Translation (CART) readers, etc. (52%);
- Managing chronic conditions, such as diabetes (50%);
- Paying for prescription medications (48%); and
- Finding a doctor who accepts public health insurance (48%).

[Read more, comment and share](#)

[Read full report](#)

9. Debate Surrounds Condition That Mimics Psychiatric Disorders

San Jose Mercury News * April 22, 2014

What Dr. Jennifer Frankovich of Lucile Packard Children's Hospital Frankovich, a pediatric rheumatologist, and Dr. Kiki Chang, a child psychiatrist, concluded was that Tessa, then 11-years old, likely had an infection or other trigger that caused her immune system to mistakenly attack her brain, dramatically changing Tessa's behavior overnight. It's a condition called PANS — pediatric acute-onset neuropsychiatric syndrome — that in some cases, if caught early enough, could be cured by commonly used antibiotics. Without early treatment, they say, children can suffer needlessly.

[Read more, comment and share](#)

10. Ranking Names Best States For Disability Services

Disability Scoop * April 17, 2014

An annual ranking of states offering the best services for people with intellectual and developmental disabilities reveals a familiar but evolving landscape.

The [analysis](#) of disability services in all 50 states and the District of Columbia being released Thursday by United Cerebral Palsy finds top performers spanning the map. In previous years, the best services were largely clustered in the Northeast and West.

Arizona claimed the number one slot in the ranking for the third year in a row. Also rounding out the 10 best on this year's list are Michigan, Hawaii, Georgia,* New York, South Carolina, Maine, Massachusetts, Ohio and Missouri. **[VOR Editor's Note:** In light of recent news reporting deaths, abuse and neglect following the transition of several hundred individuals from facility-based care, it's remarkable that Georgia makes the top 10. Is "inclusion" at any cost still "inclusion"?)

The analysis factors each state's approach to promoting independence and productivity, ensuring quality and safety, keeping families together and reaching people in need.

[Read more, comment and share](#)

11. New Fact Sheet for the National Disability Navigator Resource Collaborative (NDNRC): "Information for People on Medicaid Home and Community-Based Services Waiver Waiting Lists"

April 24, 2014 * American Association on Health and Disability (AAHD)

The American Association on Health and Disability (AAHD) is pleased to announce the publication of a new fact sheet for the National Disability Navigator Resource Collaborative (NDNRC). "Information for People on Medicaid Home and Community-Based Services Waiver Waiting Lists" is intended to provide Navigators with information about people with disabilities who are on the Medicaid Home- and Community-Based Services (HCBS) Waiver waiting list. This fact sheet can be found [here](#).

This fact sheet provides additional assistance for those assisting consumers with disabilities as it adds to a series of fact sheets which have addressed issues such as a health plans' summary of benefits and coverage, rehabilitation and habilitation therapies and devices, and prescription medication benefits. The entire list of fact sheets is available [here](#).

The NDNRC is an initiative aimed at providing cross-disability information and support to Navigators and other enrollment specialists thereby ensuring people with disabilities receive accurate information when selecting and enrolling in insurance through the Affordable Care Act Marketplaces. The NDNRC website can be found at: www.nationaldisabilitynavigator.org.

Quotable

"Impossible just takes longer." ~ David Milarch, founder, Archangel Ancient Tree Archive

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Calendar Reminders:

VOR Annual Conference Deadlines Approaching:

May 1: Annual Conference Registration Deadline (prices increases after May 1). Register [online](#) or by [mail/fax/email](#).

May 5: [Hyatt Hotel Reservation](#) Deadline to guarantee group rate and availability. All VOR events take place at the hotel.

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.

[Register today!](#)

[Week of June 9, 2013](#)

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

[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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