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September 6, 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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VOR and You

1. FANTASTIC NEWS! WE EXCEED OUR GOAL OF

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

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Your one-stop
advocacy
resource**

**Reminders:
Help VOR Grow!**

\$5,000!

A TOTAL OF \$5,472 WAS RAISED!!!

**Thank you to all VOR members who made a gift to
this campaign!!**

Dear VOR Member,

To all of you who took the time and made a gift to VOR, *THANK YOU!*

VOR's mission is to advocate for high quality care and human rights for individuals with intellectual and developmental disabilities. Our work is critical!

Here is what you invested in:

- VOR has launched a public awareness campaign designed to educate the general public regarding the tragic injustice befalling individuals with I/DD around the country, especially in those areas where a center is threatened and quality community options are lacking.
- In 2013, VOR launched a "Quality in the Community" initiative to identify and pursue uniform, humane quality standards in community settings across all states, with an emphasis on staff competency and access to specialized health care and supports. Although proponents of deinstitutionalization promise a better life in the "community," the promise is far from well-documented reality, resulting in tragedy for thousands of impacted citizens.
- VOR will continue our long-standing Legislative/Government Affairs, Legal, State Coordinator, and Family Advocacy national programs. This summer, VOR launched our new e-advocacy feature designed to enhance the effectiveness of our Legislative/Government Affairs program.
- VOR will continue our support for guardianship relationships when in the best interest of the individual, as determined by a court of law: and counter attacks on

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guardianship.

- VOR will strive to increase our membership and donor base so that we can remain a leader in the voice for choice in each state across the nation. Growth in all areas is projected; new sibling members are one target audience.

- VOR is expanding the effectiveness of our State Coordinator program to continue its advocacy support role and to assist in regionally-targeted membership and financial growth objectives.

- VOR is expanding outreach to families whose disabled family members live in community settings without adequate services. VOR continues to support efforts to assure a full range of community and facility-based options appropriate to the individual needs of all people with I/DD.

We accomplished our goal due to your support! Together, we are standing up for everyone with I/DD.

Gratefully,

Julie M. Huso

Executive Director

Tamie Hopp

Director of Government Relations and Advocacy

Legal Update

2. Illinois: Federal judge orders State to produce documents in Murray Center case

The Breese Journal (Breese, IL) * September 5, 2013

Those fighting to preserve quality care for the residents of Warren G. Murray Developmental Center in Centralia received good news on Tuesday when a federal court judge ordered the state of Illinois to produce specific documents related to the proposed closure of the facility, despite the state's motions of protest.

The order, issued Sept. 3 by Judge Marvin Aspen, relates to more than 100 documents requested by the Illinois League of Advocates

for the Developmentally Disabled, Murray Parents Association and 11 legal guardians of developmentally disabled adults, who are plaintiffs in a federal lawsuit filed against the Illinois Department of Human Services (IDHS), its director Kevin Casey, and the Community Resource Alliance.

Judge Aspen ruled that the disclosure of previously withheld materials will not hinder the state from “engaging in thorough, honest deliberations on future policies and decisions.”

The state is required to produce the requested documents within three business days.

[Read, comment and share](#)

[Read Judge Aspen’s Order](#)

Research News

3. Survey Finds Disability Abuse Widespread

Disability Scoop * September 4, 2013

VOR Editor's Note: This [newly released survey on the widespread abuse endured by individuals with disabilities](#) confirms the magnitude of a crisis that has been ignored by law and policymakers, and advocates, for far too long. We share the researchers' awe at the number of responses (2,000+ plus), which speaks to a level of engagement not usually seen in these types of surveys, and also the magnitude of the crisis. Although the survey questionnaire did not seek information about who the abusers are or where the abuse occurred, [450 letters/narratives](#) were received that contain additional background. According to Jim Stream, Executive Director of the Arc of Riverside County and co-researcher for this study, "Our survey is about the community. Decades ago, Clarence Sundrum, an individual who helped depopulate Willowbrook in New York City, sounded a cautionary note about their effort to place former residents in smaller community settings. While he and most advocates clearly believed that quality of life issues totally justified their efforts, he worried that it would be very difficult to monitor abuse in so many places. In recent years, due to investigative reports by the New York Times, abuse in these settings could no longer be ignored and a paradigm shift is underway."

Disability Scoop, September 4, 2013

More than 7 in 10 with disabilities say they've been abused, according to a new national survey, and in many cases individuals say the problems occur repeatedly.

In what's believed to be the largest survey of its kind, over 7,200 people with disabilities, family members, advocates, service providers and other professionals were polled between May and October 2012.

The [findings](#), released this week, suggest that abuse of people with disabilities is widespread across the country and often overlooked.

More than 70 percent of those with disabilities polled said they had been abused and over 60 percent of family members indicated that their loved one with special needs had been mistreated.

In about half of cases, victims said they experienced physical abuse. Some 40 percent reported sexual abuse and nearly 90 percent of those who said they had been violated indicated they were verbally or emotionally harmed. Neglect and financial abuse were also frequently cited.

"Too many people are abused too much, with very little on the response side to help in the aftermath," said Nora J. Baladerian, director of the Disability and Abuse Project, which conducted the survey. "The extent of abuse is epidemic, and the inadequate response is disturbing."

Among those who were victimized, more than 9 in 10 said they were abused more than once with 57 percent indicating they had experienced mistreatment more than 20 times, the survey found.

Incidents of abuse were not reported in about half of cases and even when authorities were alerted, survey results indicate that arrests were made only about 10 percent of the time.

[Read more, comment and share](#)
[Read the survey, findings, recommendations, data, and more](#)

[Read related news from VOR](#)

4. Few Young Adults With Autism Living Independently

***Disability Scoop* * September 3, 2013**

Young adults with autism are more likely to live with their parents and least likely to live independently after leaving high school as compared to those with other types of disabilities, researchers say.

[Read more, comment and share](#)

State News

5. California: Future of the Developmental Centers Task Force

***Fairview Family and Friends Newsletter* *
September 2013 * by Terry Debell**

For the last several months, every Sacramento legislative hearing that involved the Department of Developmental Services was marked by the very strong call to “Close the Developmental Centers” (DCs). This call came from community activists, from lobbyists, from consumers, from service providers, and from some legislators. Outside of the committee hearings, rallies have been held calling for closure of the DCs. Several organizations representing community services are working to find a legislative sponsor to close the DCs.

Diana Dooley is the Secretary of the California Health & Human Services Agency, which is responsible for the Department of Developmental Services and other Departments such as Rehabilitation, Aging, Social Services, Managed Health Care and others that are important to individuals with disabilities. Secretary Dooley has responded to the clamor to close the DCs by convening a Future of the Developmental Centers Task Force.

Surprisingly, the Task Force so far has not precisely discussed closing Developmental Centers. The agenda has been designed to

focus instead on the current DC residents, what are their needs and those of others like them in the community who may or may not be receiving appropriate services; what services are available; what services need to be developed.

[Read full article](#)

The Task Force report and recommendations will be submitted to the Legislature in November. You can follow the work of the [Task Force at the Health and Human Services website.](#)

6. California: Rally to save Developmental Center

***Sonoma Sun News* * September 3, 2013**

To show public support for keeping the Sonoma Developmental Center open, the SDC Parent Hospital Association will hold a march and rally Saturday, September 14 on Sonoma Plaza from noon to 1 p.m.

“The march and rally are a way for families of SDC clients and our supporters to express how tragic it would be if the state were to close SDC,” said event organizer Mary O’Riordan [a VOR Board Member].

The state has been reducing the populations at its four remaining developmental centers by moving clients into community care homes, O’Riordan said, and yet not all developmentally disabled people can function in that setting.

“The SDC has the expertise, professionally trained staff, and specific services needed to care for California’s most frail and severely developmentally disabled residents,” she said.

“I have heard from so many heartbroken parents whose developmentally disabled children ended up in jail, because their community care home could not handle their challenging and dangerous behaviors,” O’Riordan said. “Developmental centers provide

the safety net for those whose emotional, mental and behavioral issues, or medical frailty, make them inappropriate for community homes.”

The Sonoma Developmental Center, also known as the town of Eldridge, has been in operation for 122 years. Over the last several years it has gone from a patient population of 2,000 to less than 500. It has 1,200 employees.

The September 14 march around the Sonoma Plaza begins at noon in front of city hall and ends in the Plaza amphitheater for a rally featuring speeches by parents. Sonoma Mayor Ken Brown will also read a city council resolution in support of keeping SDC open.

7. Washington State: Two Great Letters to the Editor in Support of Choice

[Seattle Times](#)

Time for realistic solutions: Caring for the disabled in Washington

By Terri Anderson, VOR Washington State Coordinator

August 31, 2013

Close the residential habilitation centers (RHCs) is not as simple as you think. [“Editorial: Reset inequity for state’s most vulnerable,” Opinion, Aug. 25.]

The community needs to be improved and expanded. However, this should not be done at the risk of individuals leaving the RHCs or those awaiting services.

Too often, the quest to rebalance the service system — to shift institutional funding to community-based supports — neglects person-centered supports.

Has the Department of Social and Health Services implemented changes to correct the background-check irregularities discovered in the latest audit?

Do the cost comparisons parallel individuals

with similar disabilities or only the number of individuals with high needs? Similarly high needs will cost the same, regardless of setting.

Availability of medical professional services matters. How many are trained to work with the developmentally disabled? Are they willing to accept Medicaid payments?

We need realistic solutions, not oversimplified notions that only serve to limit the range of choices, including institutional care, creative family- and community-based projects that provide specialized services and residential options to people with intellectual and/or developmental disabilities.

Nice idea, in theory: Caring for the disabled in Washington

By Lyle Romer, Executive Director of Total Living Concept (Kent, WA)

September 2, 2013

A recent *Seattle Times* editorial called for the closure of state-run residential habilitation centers (RHCs) for people living with developmental disabilities. ["Editorial: Reset inequity for state's most vulnerable," Opinion, Aug. 25.]

The resulting cost savings would then be directed toward reducing the number of eligible people on waiting lists for needed services.

On the surface, this is a laudable plan. However, the simple logic of a well-intentioned strategy doesn't hold up well when one examines the cost savings of moving people from institutions and into the community more closely.

Make no mistake; for most people, we favor community living over RHCs.

What we do not support is the logic of creating the savings by shifting care to supported-living agencies whose workers receive shamefully low wages. These workers, according to the 2011 Residential Survey published by the

Developmental Disabilities Administration, make an entry level wage of \$9.88 per hour, versus \$13.32 per hour for state workers doing essentially the same work. This is a difference of 35 percent.

While we strongly favor community-support options that allow more people with disabilities to live in homes of their own, we do not support doing this by creating more overburdened and underpaid workers.

Defining Inclusion

8. A True Community! The Radical Challenge of Building a Dorm for the Deaf

[Wired](#) * August 26, 2013

Gallaudet University's newest residence hall was designed specifically for deaf students by New York City-based LTL Architects. The 60,000-square-foot building is the first to fully employ architectural principles that cater to the communication and spatial needs of the hearing impaired.

[Read more, comment and share](#)

Contrast: [A Haven for the Deaf Draws Federal HUD Scrutiny Over Potential Discrimination](#)

Social Media and You

9. Social Media Resource: Which Social Networking Sites Should Association Management Focus On?

Community Social Media Management * August 29, 2013

With so many social networking sites cropping up all the time, how does association management know which ones it should spend time and effort promoting? Facebook? LinkedIn? Twitter? Pinterest? Google+? YouTube? All of the above?

Engaging in too many sites can prove to be costly in terms of time and resources. Fortunately, a recent article on the Associations

Now website discusses a new study that investigates which social media platforms are best for organizations to invest their time in.

The “2013 Association Social Media Report,” which was conducted by Association TRENDS, shows that the most engaged organizations invest their time on Facebook and YouTube.

Regardless of which social network your association chooses to engage with its members, the key for association management is to have a strategy that drives this effort. Organizations can have a lot of actions and look at benchmarks that show they’re doing great; however, if they don’t have a strategy or it’s not working as designed, it’s a moot point.

The top five social networks that associations use are Facebook, Twitter, LinkedIn, YouTube, and Google.

Like [VOR on Facebook](#), follow [VOR on Twitter](#), view [VOR on YouTube](#), and connect with [VOR on LinkedIn](#).

Quotable

“Humility is not thinking less of yourself. It’s thinking of yourself less” ~ by C.S. Lewis

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Calendar Reminders:

***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.

*** AHCA/NCAL to host Intellectual and Developmental Disabilities (ID/DD) Day – October 6, 2013.** [Details online.](#)

VOR
836 S. Arlington Heights Rd., #351
Elk Grove Village, IL 60007

Tel: (605) 399-1624
Toll Free: (877) 399-4867
Fax: (605) 399-1631
Email: info@vor.net

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