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November 15, 2013



Speaking out for people with
intellectual & developmental
disabilities



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VOR Weekly News Update

News and views for VOR Advocates

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VOR and You

1. Comment Opportunity: National Council on Disability Quarterly Meeting Rescheduled

VOR Action Alert * November 15, 2013

NCD Meeting Rescheduled

In September, VOR issued an [Action Alert](#) making you aware of the National Council on Disability's (NCD's) Quarterly Meeting in Kansas, and the opportunity to submit comments. That meeting, postponed due to the shutdown, has been rescheduled for December 4-5, 2013 (Topeka, KS).

Public Comments

There is opportunity to submit written comments (see [VOR's Action Alert](#) for details). If you wish to speak during the public comment periods, **you must pre-register by December 2**. Kansans can speak on December 4; Non-Kansans have opportunity on December 5. [Pre-registration requirements and times for public comments are available here](#). If you pre-registered for original meeting that was postponed, you are encouraged to re-register.

VOR's Action Alert

Urge NCD to develop a reasonable policy that fully embraces services based on individual choice

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and needs, consistent with the *Olmstead* Decision:
“We emphasize that nothing in the ADA or its
implementing regulations condones termination of
institutional settings for persons unable to handle or
benefit from community settings...Nor is there any
federal requirement that community-based treatment
be imposed on patients who do not desire it.”

Because it is not clear from NCD's policies whether
original comments will be considered or if they have to
be resubmitted, so you are encouraged to take action
now, even if you did once before.

Thank you!

[Take Action. Just one Click.](#)

[NCD Meeting Agenda and Public Comment](#)

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State News

**2. Illinois: One size doesn't fit all:
Misericordia, Arc advocacy group at odds**

Chicago Sun-Times * November 11, 2013

Sister Rosemary Connelly is worried.

“There are advocates out there, some paid by
the government, who really feel that anything
big is bad, and there’s no exceptions,” she tells
me.

We’re having lunch at the Greenhouse Inn,
one of the more extraordinary restaurants in
Chicago, staffed almost entirely by residents of
Misericordia, a Catholic home for people with
developmental disabilities, particularly Down
Svndrome.

The issue is an old one. Abuses at large institutions warehousing the disabled were a scandal, particularly in Illinois, and in some places still are. The state is pushing to move people out of institutions into small, independent living residences.

Sister Rosemary feels unfairly maligned.

“If you’re big, you’re bad,” she says, summarizing critics’ thinking. “They’re very angry at us because we weaken their story, because we’re good. They really would love to get rid of Misericordia.”

[Read more, comment and share](#)

[Read Related News: Bill Choslovsky and Scott Mendel, attorneys who championed choice in Illinois to receive prestigious award](#)

3. Ohio: Hundreds rally against Gallipolis Developmental Center (GDC) downsizing: Closing process a ‘A reckless operation’

Gallipolis Daily Tribune * November 11, 2013

Recently, hundreds of current and retired employees, family members, community supporters, area labor representatives and local elected officials gathered in the Gallipolis City Park to demonstrate their support for the employees and residents of the Gallipolis Developmental Center (GDC).

Ohio Civil Service Employees Association (OCSEA) leaders and activists who work at the center staged a rally to protest the elimination of more than 25 percent of the staff and the moves of dozens of individuals out of the facility they call home. Administrators with the Ohio Department of Developmental Disabilities (DODD) announced the pending elimination of 80 jobs at GDC in mid-October.

Rally attendance overwhelmed the staff and union leadership who were grateful for the broad community support.

Speaking at the rally were Monty Blanton, OCSEA staff representative and 30-year retiree from GDC; Beth Sheets, OCSEA Board of Directors member and long-time GDC employee; Gallia County Commissioner Harold Montgomery and Troy Johnson for State Rep. Ryan Smith (R-Bidwell). The center also got wide support from labor groups that came out for the rally including members of the United Steelworkers, the Plumbers and Pipefitters, the United Food and Commercial Workers, AFSCME retirees 1184, Ohio Education Association and others.

“I’ve been committed since I left to make sure that every employee there and the people we take care of will have our community, our people there to make sure they are cared for the rest of their days,” said Blanton. “But the Department [of Developmental Disabilities] has a quite different approach.

“Even under the last administrations that we’ve had, they’ve always taken into consideration [the opinions of] the families, and they have never put them in a place where [GDC residents] were pushed out,” said Blanton. “They’ve always said that as long as the parents and their guardians wanted [residents] to stay there, they’d have a place to live. Unfortunately this administration has moved at a rapid pace of putting people out, many of whom have lived there 40, 50 and 60 years. We’ve been their caregivers for all those years. They [the DODD] have no compassion about the people who live there. ... They have moved people out we have known our entire lives. It’s been a reckless operation with no true consideration for the best interest of the

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individual.”

In addition, the statewide parent group, the Ohio League, had a statement read in support of the center and asking for an immediate end to the downsizing. State Rep. Smith through his representative also called for an immediate halt to the admissions freeze and for the Ohio Department of Developmental Disabilities to take full responsibility for the downsizing and layoffs.

GDC is one of the largest employers in Gallia County with roughly 300 OCSEA members on the nearly \$22 million annual payroll. One hundred residents call the center home. More than the fear of job loss, union activists fear that the loss of services for some of the most challenging and vulnerable residents in Ohio could have devastating results and mean fewer choices for families who need help.

Blanton said in the last two budget cycles, residents have been moved out at a rate of approximately 90 residents per biennium. He stressed that this is an alarmingly high rate with negative consequences.

“We can’t afford to move people out anymore,” said Blanton. “We are getting people back in horrible medical conditions.”

[Read more, share and comment](#)

Legal Briefs

4. California Court Rejects Bid to Oust Public Defender From Mental Health Case; Panel Says Conservatee Entitled to Independent Counsel, Even Over Conservator’s Objection

***Metropolitan News-Enterprise* * November 13, 2013**

The conservator [legal guardian] for a developmentally disabled adult may not replace the conservatee’s court-appointed counsel with

a private attorney retained by the conservator, the Fourth District Court of Appeal has ruled.

Div. Three, in an opinion by Justice Richard Aronson, denied a petition by the brother of a 51-year old woman to remove the public defender as the woman's attorney for purposes of legally mandated periodic reviews of her placement. The panel did, however, agree with the brother that there was no merit to the public defender's petition to have the woman released from the Fairview Developmental Center, a state-operated Intermediate Care Facility for Individuals with Intellectual Disabilities (ICFs/IID).

The woman, identified only as Michelle K., has an IQ of 23 and has lived at Fairview since she was 10. Her brother, George K., is her co-conservator and objected to her release from Fairview, which the public defender sought under recent amendments to the Lanterman Developmental Disabilities Services Act.

George K., her brother and co-conservator, objected to the habeas [removal] petition, retained private counsel—Jon L. Rewinski of the downtown Los Angeles firm Locke Lord—and asked that the public defender be removed as counsel and Rewinski allowed to appear in his place.

Aronson, writing for the panel, said habeas [removal] corpus was not appropriate because the very exceptional circumstances required by Hop did not apply. The public defender, he explained, did not show that George K. was acting outside his sister's best interests, or that the availability of annual reviews was an inadequate means of protecting her rights.

But allowing a private attorney retained by the conservator to represent the conservatee at a Hop hearing, over the objections of the public defender, represents a potential conflict of interest. the iustice reasoned.

“We may not substitute the good intentions of a developmentally disabled person’s parent or conservator for the person’s right to a hearing, appointed counsel, or any other constitutional safeguard Hop requires,” Aronson explained, elaborating:

“Allowing George to select Michelle’s counsel for the Hop hearing would render her right to independent counsel meaningless because George simply could replace the Public Defender with counsel who would follow George’s instructions without independently evaluating whether those instructions are in Michelle’s best interest.”

The conservator may, however, participate in the hearing and present his disagreements with the public defender, or may request that the public defender be replaced by another independent counsel, the justice said.

Aronson emphasized, however, the limited nature of Hop’s remedy and said the public defender’s role was to represent the conservatee’s best interests, not necessarily to oppose continued placement.

The case is *Michelle K. v. Superior Court* (Harbor Developmental Disabilities Foundation), 13 S.O.S. 5820.

[Read more, share, and comment](#)

Research News

5. Housing Proves Challenging For Adults On The Spectrum

Disability Scoop * November 13, 2013

Families are facing limited housing options as an increasing number of individuals with autism enter adulthood, a new survey suggests.

The vast majority of adults and transition-age individuals with autism are currently living at home and less than one-quarter said they are

on waiting lists for housing services so that they could live more independently.

Over 70 percent of respondents with autism said they would like to live in a single-family home, with a suburban setting being the most preferred option. In the case of caretaker respondents who care for individuals needing 24-hour support (35%) to those needing no support (1%), six in ten caregiver respondents preferred single-family homes.

Planned/intentional communities were a close second choice.

The findings “underscore the overwhelming need for more housing and residential support options and services,” said Lisa Goring, vice president of family services at Autism Speaks, which conducted the online survey of more than 8,600 caregivers and nearly 400 individuals with autism across the country.

“Certainly one of the take-aways for us is there needs to be more education for families in terms of what options may be available,” said Goring who pointed to housing and rental assistance vouchers as well as home and community-based services waivers as some options that are currently available.

Nonetheless, Goring acknowledged that those programs have limits and said Autism Speaks plans to advocate for expanded offerings for adults on the spectrum.

“It’s not one size fits all,” she said. “People with autism should have the same types of choices as everyone else.”

[Read more, comment and share](#)

[Read the Results of Autism Speaks Housing Survey](#)

6. People with Disabilities and the Prison System

***Disabled World* * August 2, 2013 * By Thomas c. Weiss**

People who experience forms of cognitive, intellectual, or developmental disabilities become involved not only as victims of crime but as suspects or offenders more often than people who do not experience forms of disabilities.

While there is no way to know the exact numbers of people with intellectual disabilities who are victimized in America every year by crime because they are not included in federally mandated surveys, researchers have discovered that they have a 4-10 times greater risk of becoming victims of crime when compared with people who do not experience disabilities. Children with any form of disability are 3.4 times more likely to experience abuse when compared to children without disabilities.

People with intellectual disabilities also constitute a small but growing percentage of suspects and offenders within the American criminal justice system. While they comprise 2-3% of the general population, they represent 4-10% of the population in prison and an even larger portion of the population in juvenile facilities and jails. One study examined the number of people with disabilities in state and federal prisons and discovered that less than 1% of the inmates experienced a form of physical disability, while 4.2% experienced a form of intellectual disability.

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7. Money Follows the Person 2012 Annual Evaluation Report

***Mathematica Policy Research* * October 25, 2013**

The Money Follows the Person (MFP)

demonstration program represents a major federal initiative to give people needing long-term services and supports (LTSS) more choice about where they live and receive care, and to increase the capacity of state long-term care systems to serve people in community settings. Calendar year 2012 marked the fifth full year of implementation of the national MFP demonstration. Cumulative MFP enrollment climbed to nearly 29,000 transitions by the end of December 2012, a 50 percent growth over the total number at the same point in 2011. In early 2012, three more states received planning grants bringing the total number of states to have received MFP grants to 47 (46 states plus the District of Columbia).

At the end of 2012 the total number of operating programs stood at 37, which included the four states that launched their transition programs during the year and began serving their first MFP participants: Maine, Mississippi, Nevada, and Vermont. Oregon's program was still suspended as the state conducted a review of its program's overall design and 5 states were in various stages of planning. During the year, New Mexico formally withdrew from the grant program and Florida also formally withdrew in September 2013, just as this report was being finalized.

Of the nearly 29,000 MFP Participants, 4,245 had intellectual disabilities. The majority was elderly (8,340) or physically disabled (11,285). 4,348 were unknown and 743 were "other."

[Executive Summary](#)
[Full Report](#)

Quotable, by VOR Member

"Although there is a core staff at the group home of reliable, experienced caregivers, there is also frequent turnover with other staff that

*means that at times the residents are exposed to unsafe conditions. Better pay, screening, supervision, and respect for the difficult job that caregivers have in taking care of people like my sons would help, but that requires a system that cares about them. **Self-righteous advocates clamoring to close licensed facilities and programs for people with the most severe disabilities does not help and, I think, causes care for vulnerable people to deteriorate and often results in harm to the people the advocates claim to be fighting for.**" ~ VOR Member*

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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.

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, Julv 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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