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January 3, 2014



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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For everyone so inspired by our work that you
donated last year to VOR, thank you for helping us
continue to improve and grow.

HAPPY NEW YEAR TO ALL ~

From the VOR Board of Directors and Staff.

Table of Contents

VOR and You

1. [VOR's Nominating Committee seeks individuals interested in serving on the VOR Board](#)

State News

2. **Delaware:** Repurposing Stockley
3. **Florida:** Arc Village to be nation's first: Residential community for disabled planned
4. **New Jersey:** Rochelle Park Town Committee opposed to closure of centers
5. **Kansas:** DD carve-in not approved for Jan. 1 launch: CMS and state officials continue to discuss various concerns with the state's plan

Research News

6. **Statistical Reports** for Intermediate Care Facilities for Individuals with Intellectual Disabilities

Quality in the Community: Staffing and Emergency Rooms

About VOR

Make a Lasting
Impact with a
Will Bequest

Reminders:
Help VOR Grow!

7. **E.R. Costs for Mentally Ill Soar**, and Hospitals Seek Better Way

8. **As America ages, demands are high in fastest-growing job:** It is fraught with unpredictable schedules, low pay

Quotable

Calendar Reminders

VOR and You

1. [VOR's Nominating Committee seeks individuals interested in serving on the VOR Board](#)

The VOR Nominating Committee announces its search for Board of Director Nominees.

Please respond by January 20, 2014.

The Committee is seeking applicants who:

- Have a passion for our cause on behalf of individuals with intellectual disabilities.
- Can commit time for board meetings, committee planning and meetings, assist in reaching out to current and prospective members, and attend the Annual Conference.
- Are team players who work well with others in a group.
- Listen well and are thoughtful in considering issues.
- Are willing and able to assist in development efforts.

If you are interested in learning more, please contact Sybil Finken, Chair of the VOR Nominating Committee, at finkensrc@aol.com or 712-527-3250; or Julie Huso, Executive Director

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at jhuso@vor.net or at 605-370-4652, with any questions and to receive a VOR Board application form.

Thank you for your consideration.

State News

2. Delaware: Repurposing Stockley

*The News Journal (Wilmington, DE) * October 16, 2013*

Summary: A [State Report](#) recommends opening access to Delaware's Stockley Center: Report proposes ways to expand public use of state-run complex

The Stockley Center, an underutilized state-run facility for people with developmental disabilities, also should be a medical training center, a public nature preserve, a community center and possibly the keystone of a mixed-use development, the state's health secretary said Tuesday in summarizing a years-long effort to re-imagine the complex.

"We do see this as one of Delaware's gems," said Rita Landgraf, secretary of the Department of Health and Social Services, at a conference on public health. "What can we do to enable the public to have access and see this gem?"

The 750-acre facility, just outside Millsboro near Sussex Central High School, is one of the largest parcels of state-owned land in Delaware outside of its state parks.

Established in the 1920s, it was designed to house people with disabilities, even some children, who never were expected to rejoin society.

By 1970 it had several dozen buildings and was home to hundreds of people with developmental disabilities during an era when

segregating such people in locked-down facilities was standard practice.

But as treatment has evolved toward having the developmentally disabled in group homes or other in-community settings, the number of residents dwindled.

In 2009, there were 84 adults at Stockley; today, there are 61 full-time residents getting intensive care, with some more residents in a group home on the property, said executive director Adele Wemlinger.

Several buildings on the campus are in disrepair and are no longer in use. The task force's report, issued Tuesday, recommends demolishing them.

Seeing a large property's population shrink, Landgraf and her department proposed "expanding the property's use to be as effective as possible to benefit the state at large," according to the report.

Some 307 acres already are part of a nature preserve, but a security gate controls access to the whole property, including the woodlands.

The report recommends beefing up a rudimentary network of walking trails and opening the woodlands to public access.

The state "envisions a multiple-use system which could be segmented for specific users - in wheelchairs, on bicycles, using walkers, strollers or running.

Within three years, DHSS could consider adding an indoor community sports center or outdoor playing fields, and a therapeutic horseback riding program already at Stockley could be opened up to more people, according to the report.

During the changes under consideration, Landgraf said, Stockley will continue to care for people who have serious developmental disabilities.

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The Mary Ann Coverdale Center, built in 2009 with housing wings, therapy rooms, a cafeteria and connected to a pool that wheelchair users easily can use, is staying open, she said.

"We do have individuals who still live here on site. It is critically important that we bring inclusion to them," Landgraf said.

"This was not a discussion of closing Stockley. Sometimes I hear that, out in the public. But we are not closing Stockley."

The report envisions three other major new uses of the Stockley Center.

It could house a medical residency program to give doctors-in-training more experience treating people with disabilities and house dental clinics for the poor.

The report also recommends making it possible for anyone with a disability, not only Stockley residents, to use its therapeutic pool.

Under the banner of "learning and education uses," the report suggests adding life skills and job training programs for people with disabilities, as well as a loosely defined "center for volunteer and not-for-profit groups."

In the recommendation proposing the greatest change from the status quo at Stockley, the report floats the development of "mixed-use, mixed-type construction for residential housing, offices, centers for community activities and retail."

Setting up a seasonal farmer's market and community gardens also was recommended.

[Read more and share](#)

[Read the Report and Recommendations of the Stockley Initiative Task Force](#)

3. Florida: Arc Village to be nation's first: Residential community for disabled

planned

The Florida Times Union * Dec 23, 2013

The Arc Jacksonville was recently awarded state funding and tax credits to help construct a planned neighborhood on the Southside for the people it serves: adults with intellectual and developmental disabilities.

The awarded funds can finally pave the way for the nonprofit to begin construction on the project, which has been in the works for eight years, said Executive Director Jim Whittaker.

"It's incredible," he said. "It's like a dream come true."

The Arc Village will be the first neighborhood of its kind in the country that combines independent living for adults with intellectual and developmental disabilities with a support staff on site, Whittaker said.

Families are excited about the prospect, which would provide the independence the disabled adults want as well as the support their parents want for them, he said.

The Arc Village will house about 120 adults - ages 18 and older - in 97 one- and two-bedroom apartments. It will be Florida's first planned community of affordable apartment-style rental homes for adults with intellectual and developmental disabilities. Also, it will be the state's first such complex near a bustling commercial corridor, with public transportation at the entrance and nearby employment opportunities and partnerships with families and volunteers to reduce costs.

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4. New Jersey: Rochelle Park Town Committee opposed to closure of centers

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**NorthJersey.com * Community News (Lodi, NJ
edition) * January 2, 2014**

The Rochelle Park Town Committee passed a resolution on Dec. 18 coming out against the closure of the Woodbridge Developmental Center and in support of residents in town who would be affected.

A task force assigned by Gov. Chris Christie and the state legislature decided last summer that these state-run centers would close. The centers are an institution for people with intellectual disabilities in Woodbridge and Totowa.

"There really is no rationale [to support the Governor's decision], because the national mandate states that you must give the residents of these homes a choice and their guardians or parents a choice of where you want them in private community homes or in a state facility. It might have been misinterpreted by the governor. It didn't say close these centers. It said give them a choice," [a Rochelle Park resident and uncle of a Woodbridge Developmental Center resident] said.

[Read more, comment and share](#)

5. Kansas: DD carve-in not approved for Jan. 1 launch: CMS and state officials continue to discuss various concerns with the state's plan

KHI News Service * Dec. 27, 2013

TOPEKA — Kansas will not be able to move forward Jan. 1 as planned with its KanCare expansion intended to include long-term supports for the developmentally disabled.

Instead, officials at the federal Centers for Medicare and Medicaid Services continue to talk with state officials about various concerns

they have with the state's plan [as outlined in [CMS letter to the State](#)].

Officials said the lack of a CMS sign-off for the Jan. 1 start more likely would result in a delayed approval after various changes are made to the plan as opposed to outright rejection of what has been one of the more controversial components of Gov. Sam Brownback's ongoing Medicaid program makeover.

Kansas Sen. Laura Kelly said there were four main areas of concern with the administration's plan as outlined by federal officials and others:

- * The number of disabled people on the state's so-called "underserved list."

- * Concerns about whether the state can guarantee prompt payments for services by the state managed care companies to DD service providers.

- * The state's organizational structure for its KanCare ombudsman. Critics say the ombudsman should not be directly employed by a state Medicaid agency in order to assure greater independence.

- * Concerns about "notices in the state's 1915C waiver and proposed 1115C waiver amendment."

Brownback officials subsequently issued a [statement](#) saying they would continue talks with CMS through Feb. 1 — a date not mentioned in the letter from CMS — in an effort to resolve or respond to the concerns that have been raised and, during that interval, develop a new implementation timeline for the KanCare expansion, to which they said they remain fully committed.

Interhab, the association that represents most of the state's Community Developmental Disability Organizations, filed [comments](#) earlier this week with CMS, newly outlining that group's ongoing trepidations with the proposed carve-in

of DD services.

Earlier this month, the National Council on Disability, a federal advisory panel, urged CMS officials to delay for one year the state's request to include long-term DD supports and services in the state's sweeping managed care plan. Medical services for the developmentally disabled were included in KanCare on Jan. 1, 2013, when virtually all the state's 380,000 Medicaid beneficiaries were moved into managed care plans run by three major, for-profit insurance companies.

Advocates for the disabled said they were pleased that CMS had withheld approval.

[Read more, comment and share](#)

Research News

6. Statistical Reports for Intermediate Care Facilities for Individuals with Intellectual Disabilities

ID/DD Digest * December 2013 * American Health Care Association

The American Health Care Association's (AHCA) Research Department has released its October 2013 update on [LTC \[Long Term Care\] Stats: Intermediate Care Facilities for Individuals with Intellectual Disabilities \(ICF/IID\)](#).

[Additional LTC research is available from AHCA here.](#)

Quality in the Community: Emergency Rooms and Staffing

7. E.R. Costs for Mentally Ill Soar, and Hospitals Seek Better Way

New York Times * December 25, 2013

Summary: Deinstitutionalization has led to an increase in Emergency Room admissions. at an

increase cost and decline in appropriate care: “The problem has been building for decades as mental health systems have been largely decentralized, pushing oversight and responsibility for psychiatric care into overwhelmed communities and, often, to hospitals . . . When the economy plummeted in 2008, North Carolina, like other states, reduced funding to community programs. In all, the state spends 20 percent less on community mental health services than it did a decade ago.”

[Read more, comment and share](#)

8. As America ages, demands are high in fastest-growing job: It is fraught with unpredictable schedules, low pay

Bloomberg News * November 20, 2013

BRIDPORT, Vt. — Amanda Sheppard’s survival tactics are finely tuned after seven years as a personal care aide, the fastest-growing job in America. Her family won’t go hungry.

Supermarket shopping can be a luxury because of what she does for a living, making \$9.78 an hour, with no benefits or guaranteed hours. She is one of more than 900,000 personal care aides — caregivers who provide comfort and companionship for the elderly and disabled and perform daily chores so they can remain in their homes. It’s a signature occupation of a post-recession economy creating mostly low-wage jobs.

The number of PCAs, as they’re called, will increase 70 percent from 2010 to 2020, making it the fastest-growing job in the country, according to the Department of Labor. The trade is exploding as the country ages and Medicaid focuses on keeping people out of nursing homes and other facilities. That saves money and requires an army of caregivers like Sheppard who are helping fill the growing ranks of the working poor.

Sheppard, 31, is a combination groomer, cook, housekeeper, guardian and friend. Her schedule is typical for a PCA: spotty and unpredictable. She has one full-fledged client and two who can't pay her at the moment. She tends to them anyway.

As an independent contractor, not on the payroll of a home care company, Sheppard isn't in the Bureau of Labor Statistics tally. While the government counted 985,230 PCAs in 2012 — that's a 44 percent increase from 2010 — there were an additional 800,000 like Sheppard who weren't included in the category, "and that's a very conservative estimate," says Abby Marquand, an associate director at the New York-based Paraprofessional Healthcare Institute, an advocacy group for direct-care workers, 90 percent of whom are women.

The average hourly pay for the PCAs the government tracked in 2012 was \$10.01, according to the Bureau of Labor Statistics. Adjusted for inflation, their wages fell 5 percent over a decade. Sheppard has earned the same state-set rate since she started in 2006, and inflation means her real wage has dropped 14 percent. Vermont will give some PCAs a raise this month, to \$11 an hour. That's in the lower-wage category of most of the jobs produced in the labor market recovery after the 2007-2009 recession, according to a study by the National Employment Law Project in New York, which receives funding from foundations and unions. The study found that 58 percent of those created from 2010 to 2012 paid \$13.83 an hour or less.

In the home care sector, workers make so little that 50 percent depend on some form of government assistance, according to Dorie Seavey, the Paraprofessional Healthcare Institute's policy research director.

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Quotable

Life is like a camera.
Focus on what's important,
Capture the good times,
Develop from the negatives, and if things don't work
out,
Take another shot.
~ Unknown

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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,
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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