



Speaking out for people  
with intellectual disabilities  
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## VOR Weekly News Update

News and views for VOR advocates

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### Special Education Resources

#### Coming Up:

\*Stephanie Vance's E-Advocacy Course #4 ([members only](#))

\*P&A releases report acknowledging problems in the community and seeks more funding

### VOR and You

1. [Call for VOR Board of Director Applicants](#)

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VOR's Nominating Committee seeks individuals interested in serving on the VOR Board of Directors. Visit [VOR's website](#) for details.

2. REMINDER: [Save the Date](#): VOR 2012 Annual Conference, Legislative Briefing and Washington Initiative, June 9 - 13, 2012 in Washington, D.C.

### Action Center

#### 3. White House Resumes Monthly Disability Calls

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The White House has resumed monthly disability calls to update stakeholders on various disability issues as well as to introduce stakeholders to persons who work on disability issues in the Federal government.

This call is open to everyone. If you would like to be added to the White House Disability Group email distribution list, please send an email to [disability@who.eop.gov](mailto:disability@who.eop.gov) with your name, organization, city and state.

You can submit comments and questions at [disability.gov](http://disability.gov), which may be addressed during a monthly call. VOR advocates are encouraged to share their concerns regarding federally-sponsored deinstitutionalization activities by the Department of Justice (DOJ) and the Administration on Developmental Disabilities (ADD) programs (Protection & Advocacy systems and DD Councils). For more information, contact Tamie Hopp at [thopp@vor.net](mailto:thopp@vor.net).

### The Impact of Deinstitutionalization: Losing Safety Net Services

#### 4. CT: Edwin Sanchez's ordeal in a community group home

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**The STS Blog \* January 18, 2012 By David Kassell,  
Communications Director, Southbury Training School (STS)  
Home and School Association**

*Comment from author: This post on the STS blogsite is about the ordeal faced by James Sanchez and his brother, Edwin, after Edwin was moved from STS to a community-based group home a number of years ago. I think this case demonstrates, as well as any I've ever seen, the value and importance of maintaining state-run Intermediate Care Facilities such as STS. [Comments](#) on this post are greatly appreciated.*

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Community-based care in group homes is certainly appropriate for the vast majority of people with intellectual disabilities. But it doesn't work for everyone. If you don't believe that, talk to James Sanchez. If anyone's experience illustrates the continuing need for developmental centers such as the Southbury Training School, the experience of James and his brother Edwin does.

It was 1979, and STS at that time was still open to new admissions. Edwin was accepted.

James maintains that Edwin thrived at STS during the next 20 years. While he first lived in a large dormitory with eight to 10 beds in a room, the conditions steadily improved at STS, and Edwin was eventually moved to one of many new, smaller cottages on the campus.

The doctors and other staff at STS were able to put Edwin on medications that kept his aggressive behavior under control while allowing him to function successfully. He attended day-work programs in the community and enjoyed outings to restaurants, movies, swimming pools, and camping grounds.

Edwin, like other STS residents, also had the freedom to roam the STS grounds under the watchful eyes of the staff.

“It was a form of independence,” James says. Edwin liked to walk from his cottage to the administration building — the length of about two football fields — in order to get a soda and chips from the vending machines there. He was taught how to wash his own clothes, how to set the table for dinner, and how to interact appropriately with other people.

Edwin knew everyone at STS and everyone knew him. “It’s like a large family,” James says. Even the firemen on campus knew and liked Edwin. Once, James was pulled over by a state trooper while driving on I-84. “He (the trooper) asked me where I’d been and where I was going, and I said I’d been visiting my brother, Edwin, at the Southbury Training School,” James says. “Oh, you mean Eddie?” James recalls the trooper as saying. “He gave me a break.”

But things were about to change for Edwin. [Click here to read about Edwin’s ordeal in the community and the fight by James to get him back home to STS.](#)

##### **5. Tennessee: Staff serving former ICF/MR residents cited for neglect**

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[Marshall Tribune \(Tennessee\)](#) \* January 20, 2012

Two women, employed by Independent Opportunities Inc. (IOI), indicted by the Marshall County grand jury face prosecution on felony counts alleging neglect of William Robert Cummings, 40, who has severe intellectual disabilities.

Six months ago, a supervisor for the state-contracted company providing food, clothing and shelter for the man, had to crawl through a window into a Dodson Drive home because the front door couldn’t be opened.

Inside, she found a former Nashville resident of Clover Bottom Developmental Center naked and chewing on his clothes while two caregivers were allegedly asleep on the job in another room.

The two women "were employed by Independent Opportunities IncThe two women allegedly "deprived services to ... Cummings that were

necessary to maintain ... [his] health and welfare..." the indictment states.

Cummings' mother said his ailment is a result of a birth defect. He is helpless without constant care. He also has pica, characterized by an appetite for substances with no nutritional value.

"He will eat the window sills off if you don't watch him," the mother said. "Lots of nights he won't sleep. He must have someone with him at arm's length ... He can't talk, walk or feed himself alone. He depends on his caretakers," she said.

"Independent Opportunities Inc. provides services through the Department of Intellectual and Developmental Disabilities (DIDD,)" the Tulsa-based company said in a prepared statement.

"It is unfortunate to receive an allegation of this nature," IOI said, having been asked specifically about the two employees who have been indicted - not convicted, "but we commend the staff that discovered and reported this incident as required by DIDD. Cummings has been receiving IOI supports since 2000 following his move from Clover Bottom Developmental Center a result of a federal lawsuit filed against the state 17 years ago.

"Everybody who knows me knows it's my son. It's a small town," said his mother.

"Most of the people who work with him love him and treat him like he was one of their own. That's really all I ask. He's a child, really, mentally."

## **6. Dental Care Hard To Come By For Many With Special Needs**

[Disability Scoop](#) \* January 19, 2012

Many dental professionals are unwilling to accommodate adults with developmental disabilities and the consequences are extending far beyond the mouth.

In what experts are calling a national crisis, few dentists are treating individuals with special needs, especially once they reach adulthood. At the heart of the problem: money and knowledge. Medicaid offers notoriously low reimbursement rates for dentists, so few accept the government health insurance program. And in some states, Medicaid doesn't cover oral care at all.

Meanwhile, some dentists are simply uncomfortable meeting the needs of individuals with disabilities since they often don't receive training on how to serve this population while in dental school.

And the consequences can be far reaching. Without dental care, something as simple as a toothache can lead to a meltdown for those with disabilities, experts say.

Some nonprofit groups — including Special Olympics — are working to meet the need by offering free dental care, but they say their efforts are not enough. They're urging the federal government to take action by identifying those with disabilities as a medically underserved group, reports ABC News. [To read more click here.](#)

## **7. Health Care: Autism Units Lacking At Nation's Hospitals**

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**Disability Scoop \* January 12, 2012**

*Editor's Note: As specialized settings close, resources (including health care services) are lost. Hospitals, even psychiatric hospitals with experience treating and caring for people with mental illness, are not prepared to serve people with developmental disabilities, even disabilities as prevalent as autism. As this article indicates, there are only (remarkably) nine psychiatric hospitals around the country that include a unit for people with autism and other developmental disabilities.*

More psychiatric hospitals are working to meet the needs of a burgeoning population of kids with autism and other developmental disabilities, a [new study](#) finds, but despite significant growth, services remain limited.

Researchers found just nine hospital units across the country that focus specifically on the needs of those with autism and other developmental disorders. That's more than twice the number that existed 10 years ago.

Nonetheless, the specialized programs are far from meeting the national need, accounting for just 137 beds at psychiatric hospitals. Most of the facilities are concentrated in the Northeast and none are located west of Denver, according to the study published in the Journal of Autism and Developmental Disorders late last month.

Researchers surveyed officials at all of the specialized facilities and found that kids are most often admitted due to problems with aggression, self-injury or elopement. All nine units reported employing both child psychologists and behavioral specialists to best meet the children's unique needs.

But the biggest challenge the hospitals face is finding adequate services for the children once they are discharged from inpatient settings, according to the study led by Matthew Siegel of the Tufts University School of Medicine.

## **8. Incarceration: Texas' failure to fund mental health treatment leaves hundreds stranded in jails around the state**

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**The San Antonio Current (excerpts) \* January 4, 2012**

Defendants with severe mental illness land in the criminal justice system where they're forced to languish for months behind bars while an overburdened state hospital system struggles to find room. The

state's mental hospitals have long hovered at or near full capacity, with roughly 2,400 patients at any given time pushing the system to its limit, according to numbers from the Department of State Health Services.

In 2005, the Texas Commission on Jail Standards and the Texas Correctional Office on Offenders with Medical or Mental Illness (TCOOMMI) reported that at least 17 percent of adult offenders inside the state's county jails had previous contact with state's mental health care system, though anecdotal evidence suggested the number of mentally ill inmates could actually be much higher. Mental illness floods the criminal justice system largely because communities lack comprehensive treatment options, the report found. Many in the jails, the report speculates, could be unidentified, undiagnosed, and without the legal assistance to even push for needed competency hearings. [Read More.](#)

### **Special Education Resources**

- Wrightslaw, a web-based special education law and advocacy resource parents, advocates, educators, and attorneys, with an emphasis on parents as the “catalysts for education reform,” has published its annual [top 10 lists](#) of articles, topics, cases and blogs for 2011.
- [Florida parents seek help from special-education advocates](#)
- [Feds Crack Down On Schools Skirting Disabilities Act](#)

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