



Speaking out for people with intellectual and developmental disabilities

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## VOR Weekly News Update

News and views for VOR advocates

VOR is a national organization that advocates for high quality care and human rights for people with intellectual and developmental disabilities

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## VOR and You

### **1. Reminder: VOR Membership Challenge Campaign: Help VOR Grow!**

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Please take a moment and reach out to your family members, individuals in your parent/family group, friends and others you may know and share your passion about VOR and our mission – and encourage them to [join VOR](#).

VOR is the only national advocacy organization that advocates for high quality care and human rights for all people with intellectual and developmental disabilities.

It is time for change: we must strengthen our family advocacy, enhance our grassroots involvement and increase our membership numbers.

Winston Churchill stated, "*There is nothing wrong with change, if it's in the right direction.*"

We are planning in a future direction that will position VOR to be proactive and have a strong voice for your loved ones and their rights to quality care and the right to live in a home that is right for them.

Thank you to each of you for your continued loyalty through your [membership](#) and [donations](#).

**MEMBERSHIP CHALLENGE REWARD:** Every VOR member that recruits five new members in the next six months will have their name placed in a drawing for a free two year membership!! ***Thank You!***

**2. Take Action: Spread the word in support of Bede Vanderhorst, teen with Down Syndrome who was not allowed to fly first class because of his disability – Outrageous!**

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***The Huffington Post* \* September 4, 2012**

A Southern California family decided to splurge on first-class plane tickets for the first time but were denied entry onto the plane because their son has Down Syndrome, they claim.

[Read more, view video and respond](#)

**National and State News**

**3. NATIONAL: Two Campaigns Differ Sharply on Medicaid, Seeking Vast Growth or Vast Cuts**

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***The New York Times* \* August 31, 2012**

The outcome of the Presidential election will probably have an immediate and profound effect on Medicaid.

the joint state-federal program that provides health care to poor and disabled people. Few other issues present a starker difference between the Republican and Democratic tickets.

[Read more](#)

#### **4. NATIONAL: Feds Begin Rollout Of Community Living Program**

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##### ***Disability Scoop* \* September 5, 2012**

A new federal program designed to expand community living options for people with disabilities is one step closer to reality this week with the first state cleared to take part.

The Centers for Medicare and Medicaid Services said Tuesday that California will be the first to participate in the Community First Choice Option. The program, established as part of the Affordable Care Act, offers states more Medicaid dollars for community living in exchange for agreeing to eliminate caps on the number of people served in the community.

Under rules issued earlier this year for the Community First Choice Option, states which opt to participate can qualify for a 6 percentage point bump in funding to provide attendant services and supports in the community for Medicaid beneficiaries who would otherwise require care in an institution. People with disabilities who are served under the program must receive supports in accordance with their preferences under a so-called "person-centered plan."

[Read more](#)

#### **5. NEW JERSEY: Former State Disability Official Cites the Danger of Injury, Death when Transferring Developmental Center Residents to Community**

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##### ***The Alternative Press* \* by Dr. Salvatore Pizzuro (Guest Column) \* September 3, 2012**

A former State official who directed services for people with developmental disabilities in New Jersey has declared that New Jersey's plan to close two developmental centers and place the residents in the community is flawed and presents unacceptable risks. Bernie White, who served as the Deputy Director of the New Jersey Division of Developmental Disabilities for 32 years, revealed that a high rate of mortality arose nationally when residents were transferred from

the large developmental centers to the community. Currently, the State plans to close the Woodbridge and Totowa developmental centers. According to White, 73% of the Woodbridge residents are non-ambulatory, making the transfer to community settings highly dangerous.

Two years ago, the Division of Developmental Disabilities listed the necessary components for a successful transfer to the community. Those components included accessible housing, healthcare, nursing services, mental health services, physical, speech and occupational, therapies, social and recreational activities, and opportunities for employment.

Sources have indicated that virtually no prospective community placements have all of these components and the transfer of non-ambulatory residents from Woodbridge to the community will likely result in an inordinate number of deaths during the first year.

Secondly, the plan for such transfers does not include the guarantee that the residents will live closer to their families, which is considered a necessary ingredient for survival and success.

[Read More](#)

## **6. FLORIDA: Feds slam state for warehousing disabled children in nursing homes**

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***Bradenton Herald* \* September 7, 2012**

Florida health and disability administrators have been systematically dumping sick and disabled children — some of them babies — in nursing homes designed to care for elders, in violation of the youngsters' civil rights, the U.S. Justice Department says.

Hundreds of Florida children are spending their formative years in hospital-like institutions, sometimes growing up in the equivalent of hospital rooms with virtually no education or socialization, the Justice Department's Civil Rights Division wrote in a 22-page letter to Attorney General Pam Bondi. Bondi's office is defending the state against a previously filed lawsuit that claims the institutionalization of children violates federal law.

The letter, written by Assistant U.S. Attorney General Thomas E. Perez, is the federal government's first attempt to weigh in on the controversy. At the end of his letter, Perez outlined a series of steps the state

could take to reduce its reliance on nursing home beds for frail children. If state leaders fail to “correct” the practice, Perez wrote, “the Attorney General may initiate a lawsuit” of his own.

In a court pleading last June, AHCA said federal law allows the agency to “place appropriate limits on a service based on such criteria as medical necessity” and cost-cutting, but does not have a policy in support of placing children in nursing homes.

In its report, though, the Justice Department said such individual decisions — some of which are “applied irrationally or without appropriate consideration of the child’s needs” — reflect a systemic policy that forces families to institutionalize their loved ones. During its investigation, the DOJ visited large nursing homes that collectively house more than 200 children in Miami, Fort Lauderdale, Orlando, Tampa and St. Petersburg, interviewing families and caregivers along the way.

[Read more](#)

### **7. CALIFORNIA: Bills to reform developmental center police reach governor. Two measures aim to strengthen protections of patients after reports of abuse**

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#### **The Bay Citizen \* September 5, 2012**

Two bills that would require outside police and advocates to be informed about alleged crimes against the developmentally disabled at California’s board-and-care institutions have reached Gov. Jerry Brown’s desk.

Brown has 30 days to sign the legislation – SB 1051 and SB 1522 – into law or veto the measures. Both bills are designated urgent, so they take effect immediately should the governor approve them.

State lawmakers introduced the legislation in response to reporting by California Watch, sister site of The Bay Citizen, which found the in-house police force at developmental centers for years failed to competently investigate cases of patient abuse and suspicious deaths.

The centers are home to nearly 1,700 patients with cerebral palsy and profound intellectual disabilities in Sonoma, Tulare, Orange, Los Angeles and Riverside counties. The police force, called the Office of Protective Services, patrols and handles criminal

investigations at the state-run facilities. SB 1051, sponsored by state Sen. Carol Liu, D-Glendale, and state Sen. Bill Emmerson, R-Riverside, would make two significant changes to the force and its work. First, the bill would mandate that developmental centers notify Disability Rights California, a protection organization, of all unexpected or suspicious deaths, sex abuse allegations and any report made to law enforcement. Second, the force's police chief would be required to have law enforcement experience before overseeing criminal investigations.

SB 1522, sponsored by state Sen. Mark Leno, D-San Francisco, would require the centers to immediately alert outside law enforcement of patient deaths, sexual abuse, assaults with a deadly weapon or severe injury, and unexplained broken bones. The state Senate and Assembly passed the bills with unanimous votes last week.

[Read VOR's Position in Support of SB1522](#)

### **Sibling's Voice**

#### **8. Autism can have large effects, good and bad, on a disabled child's siblings**

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***Washington Post* \* September 3, 2012**

One of the least fun moments I recall from my years of growing up with an autistic brother was when he bit me on the cheek — just in time for my class photo. I was 12 and he was 11. I went into school with visible bite marks, and when they sat me in the chair for my solo shot, I told them that the cat had done it. That's one of the bad stories. As for a good one . . . um, to be honest, I have a hard time coming up with much.

I know that people are warmed by stories of siblings who selflessly shower the disabled child with love, attention and support. I think that's great, too. And it's for real for some siblings. But for many of us, relating to a sibling who is on the autism spectrum can be complicated. The challenges to a warm, close relationship are many. Normal sibling rivalry doesn't work, because it can never be a fair fight.

Here's what siblings often are up against, particularly when a brother or sister has more severe autism..

There is plenty of fertile ground for building resentment. And then feeling guilty about feeling resentment. Because after all, even as youngsters

we do understand that our disabled sibling cannot help being disabled.

The feeling that our needs come second is echoed in the small volume of research on how autism affects siblings. More research has been done on how autism impacts the family. Most of it, however, has focused on how parents are affected.

What intrigued me — both as an autism sibling and as a family physician whose patients include autism siblings — was the dearth of studies looking specifically at the sibling relationship.

Charley Moskowitz, a social worker in New York who works in a program designed to help children adjust to disabled siblings in the home, says that after years of working with such families, it's clear "there is no such thing as a typical sibling."

In sessions where non-autistic brothers and sisters get together for a day of shared activities, the kids have a chance to talk about their experience. They can vent, examine their feelings and learn from their peers — boys and girls from other homes with autism.

Several themes repeat themselves, Moskowitz says. "These children feel extremely responsible," she says. "They feel neglected, they feel that their home is in turmoil, that nothing will be normal for them."

How parents handle the situation — whether it is a temper tantrum in public, other annoying behaviors or daily behavioral interventions — is extremely important, according to Moskowitz and Ryan Macks, a child psychologist at Cincinnati's Children's Hospital and one of the few researchers on sibling impact.

"One of the things we know," Macks says, "is that the mental health of the parent, their coping skills, tends to be the primary predictor in terms of how the sibling is going to handle the situation."

[Read More](#)

**Related:** [VOR's Sibling's Voice Webpage](#)

### **Quotable**

*"Although they constitute a small subset of all persons diagnosed with mental illness, the most severely ill patients are in dire need of the specialized, intensive treatment that has been delivered since the early 1830s through state hospital systems. The elimination of these systems is producing significant public and personal consequences in communities nationwide." ~*

["No Room at the Inn: Trends and Consequences of](#)

[Closing Public Psychiatric Hospitals,](#)” Treatment  
Advocacy Center (July 2012).

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