



Speaking out for people with intellectual & developmental disabilities



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**Reminders:  
Help VOR Grow!**

**Challenge!  
Recruit 5 New  
VOR Members  
Today!**

## VOR Weekly News Update

News and views for VOR Advocates

**[Registration now open for VOR's Annual Conference and Washington Initiative, June 8 - 12, 2013 in Washington, D.C. Please join us!](#)**

***Did you receive this as forwarded e-mail? If so, someone thought you would benefit from VOR's information. Please consider [joining VOR](#) and receive this E-News Update publication weekly!***

### **VOR and You**

1. Holly Honeymoon: A rare victory is Christmas present for one family and hope for others
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4. Lobbying Rules for (c)(3)s: Keeping It Legal

### **National News**

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### **State News**

7. New Jersey: Closing of New Jersey Facilities Carry Pain for Families of Disabled
- Quotable**, by RMA

### **Calendar Reminders**

\* **Deadline Today! [February 1, 2013](#)**

VOR [Quality Matters Survey](#). Deadline Extended. Your voice counts. Please take VOR's Quality Matter Survey.

\* **[Wednesday, February 13 at 12:00 pm central / 1:00 pm mountain](#)**

VOR State Coordinator and Member Webinar (free). Registration details coming soon

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

**VOR.net:  
Your one-stop  
advocacy  
resource**

\* **Sunday, June 9, 2013**

VOR Annual Conference \* Washington, D.C. [Registration now available. Details online.](#)

\* **Begins Monday, June 10, 2013**

VOR Washington Initiative (Begins Monday, June 10, 2013) \* Washington, D.C. [Details online.](#)

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## **VOR and You**

### **1. Holly Honeymoon: A rare victory is Christmas present for one family and hope for others**

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**VOR \* January 31, 2013**

Excerpts ([full article here](#))

After an eight year journey, Virginia (“Ginger”) Massa now calls Holly Center home.

Families in similar situations across the country will appreciate what a monumental challenge it was for Ginger and her family to secure placement at Holly Center. As a Medicaid-licensed intermediate care facility for persons with intellectual disabilities (ICF/ID), becoming a permanent resident meant bucking a state and national trend.

Ginger’s good fortune is not lost on Mary Reese, Ginger’s stepmother and a [VOR Board Member](#). As a national advocate, Reese knows all too well that Ginger’s struggle for the past eight years is one shared by thousands of individuals across the country. She recognizes that her job as an advocate is not done.

Ginger’s long journey, while certainly peppered with significant hurdles along the way, is not without success that will benefit others.

One early [legal victory](#) was the 2006 decision by the Maryland Court of Special Appeals ruling which stated that Ms. Massa was denied due process when Maryland’s Secretary of the Department of Health and Mental Hygiene refused to even hear her request for an ICF/ID placement. The controlling statute was found unconstitutional because it only provided for a hearing when ICF/ID admission was approved.

## Reminders: Help VOR Grow!

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No such hearing right was offered when ICF/ID admission was denied. Ginger's fight changed state law which now requires appeal hearings in each case.

"Thanks to VOR, we had access to outstanding legal representation and advocacy to carry this cause forward." Sidley Austin attorneys provided pro bono representation to Ginger and Mary for more than 6 years.

In the words of Jeffrey Green, Mary and Virginia's attorney, "Legal victories are nice, but a client ultimately doing well is better. I don't think I've been more heartened by anything in a long while than by reading that Virginia 'has taken to life at Holly Center like a duck takes to water.' That's the very best news of all."

[Read complete article](#)

[Read more about Mary and Virginia's legal victory here](#)

### 2. VOR's Elevator Speech

#### VOR Marketing and Communications Committee \* January 2013

An "elevator speech" short, 15-20 second statement about an organization that is easy to say and quickly informs the listener, keeps their attention, and leaves them wanting to learn more.

VOR's Marketing and Communications Committee put together the following "elevator speech" for VOR members' use when talking with public officials, prospective members, advocates and others about VOR. The first sentence is our actual mission statement. The points that follow sum up what VOR is all about. As Hugo Dwyer, Chairman of the Committee, stated, "This elevator speech contains our mission and main talking points. Members, however, should feel free to use their own words to get across these main points if they feel comfortable doing so: the 'speech' should

be consistent with our template but also reflect the character of the person delivering it.”

**VOR’s Elevator Speech:**

*VOR is a national nonprofit organization advocating for high quality care and human rights for all people with intellectual and developmental disabilities.*

*As the only national advocacy organization supporting a spectrum of care options, we offer hope and support for people with intellectual and developmental disabilities, and their families, who are working to protect or secure necessary services.*

*We advocate for appropriate care at all levels of government.*

VOR members are in a unique position to promote VOR and our mission on behalf of people with intellectual and developmental disabilities with others. We hope this “elevator speech” assists our dedicated members in their outreach and awareness on VOR’s behalf.

**3. Nothing to lose, and everything to gain, from collaboration**

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***Richard Male and Associates (RMA)***

Dear VOR Members:

In keeping with the following RMA article on the power of collaboration, we encourage you to share your ideas with VOR about how we can collaborate more with your organizations and others in your area. Think outside the box and assist in VOR’s growth!

**From RMA:**

Too often the words “cooperation” or “collaboration” sound more like “merger.” Executives and board leaders often feel threatened by the idea of sharing information or resources with another nonprofit, as if the inevitable outcome is that someone loses ground, gets overshadowed, or even swallowed up.

RMA's counsel, however, is based on the idea of collaboration as a very long and gradual continuum. We encourage our clients to consider small steps. The goal is appreciating the value of reaching out, in whatever form that might take, without expectation that anything follows.

[Read more](#)

#### **4. Lobbying Rules for (c)(3)s: Keeping It Legal**

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**Source: Salsa Labs, January 29, 2013**

*[Note: This is helpful information for nonprofit organizations, but should not be construed as legal advice. Nonprofit organizations are encouraged to review IRS lobby allowances with an attorney].*

While many charities understand that they can lobby, they hesitate to do so as they are afraid of breaking the rules. Watch this webinar to learn how you can give your mission a voice in the policy debates while staying within the law. The webinar will help public charities understand:

- What counts as lobbying and what doesn't
- The difference between the "501(h) election" and the "no substantial part" test
- How to calculate your organization's lobbying limit
- Fundraising for lobbying, including rules for foundation funding

[Watch the Webinar](#)

[Review the Slides](#)

#### **National News**

#### **5. From AHCA: VOR Affiliate Comments on NCD's Call for Institutional Closure**

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**DD Digest \* American Health Care Association \* January 2013**

The Massachusetts Coalition of Families and Advocates, Inc., also known as COFAR, is the Massachusetts affiliate of VOR. COFAR recently commented on its [blog](#) about the

National Council on Disability's (NCD) new policy paper and "toolkit" entitled "Deinstitutionalization: Unfinished Business," which calls for the closure of all institutions for individuals with ID; as well as a subsequent NCD letter that touched on the issue to Vice President Biden. NCD is a small, independent federal agency charged with advising the President, Congress, and other federal agencies regarding policies, programs, practices, and procedures that affect people with disabilities.

**Note:** AHCA also included a note about VOR's Annual Conference in its [DD Digest](#); and VOR representatives Mary Reese and Larry Innis, will be presenting at AHCA's DD Fly-In.

[Read the DD Digest \(January 2013\) here](#)

## **6. From Treatment Advocacy Center: "Keep, and expand, treatment options"**

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**Variety \* Editorial by Doris Fuller, Executive Director, Treatment Advocacy Center**  
Excerpts

There is no evidence that individuals who receive treatment for severe mental illness are more dangerous than the general population. But an estimated 1% of the 7.7 million have been found to pose a danger to themselves or others when untreated, and that's 77,000 people at risk to harm someone while experiencing symptoms from a treatable illness.

Over the past half-century, about 95% of the nation's public psychiatric beds have been eliminated.

[Read more](#)

## **State News**

### **7. New Jersey: Closing of New Jersey Facilities Carry Pain for Families of Disabled**

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**NorthJersey.com \* January 27, 2013**

Mary Ellen Scesa has spent 42 of her 46 years living at the North Jersey Developmental

Center in Totowa.

If it were up to her parents, the center would continue to be her home indefinitely.

“The care she gets there is phenomenal,” said Louis Scesa, her father. And its proximity to their New Milford home — just a 25-minute drive — allows them to visit Mary Ellen regularly.

But that won’t be an option for the Scesas much longer. The state plans to close the Totowa facility and a second center in Woodbridge within five years, and officials are telling family members that displaced residents will likely be moved to South Jersey if they choose to remain in a state center.

The Scesas and other families find themselves caught up in a major restructuring of the state’s system of care for developmentally disabled adults — individuals with conditions ranging from intellectual disabilities to autism to cerebral palsy. When the reorganization is completed, institutional care will have disappeared from the heavily populated northeastern part of the state, a victim of fiscal realities, changes in public policy and regional New Jersey politics.

Families from the North Jersey and Woodbridge centers have organized a group called Save Residents’ Homes at Developmental Centers.

They’ve met with Thomas York, a Pennsylvania-based attorney who filed a lawsuit on behalf of residents of the Vineland Developmental Center in Cumberland County.

York said any legal action would have to focus on claims that the state is violating the rights of center residents, not on whether the state can close an institution.

“We cannot stop a particular developmental center from closing or directly interfere with the state’s decision to close an individual

developmental center,” he explained. “What we can do is protect individual rights. Our position is that in most cases that level of services needed cannot be met in the community.”

He added that relocating disabled individuals far from their families’ homes also might be interpreted by a court as preventing them from receiving adequate care, because family involvement is critical to their well-being.

[Read more](#)

**Quotable**

*“Positive outcomes occur all along the continuum if you’re willing to explore them.” ~*

Richard Male, RMA

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**JOIN VOR. DONATE TO VOR. MAKE A DIFFERENCE**

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