



August 9, 2013

# VOR Weekly News Update

News and views for VOR Advocates

[About VOR](#) \* [Refer a Friend](#) \* [Donate](#)

## Table of Contents

### VOR and You

**1. Sharing our Success:** In celebration of 30 years and new initiatives, VOR offers complimentary subscriptions!

**2. Goodbyes are never easy**

**Supporting an array of housing options for people with autism, supporting choice**

**3. Designing a Community for Families Living with Autism:** If you build it, we will come

**4. Will Government Limit a Spectrum of Housing Options for Autism?**

**5. Spotlight on National Association of Residential Providers for Adults with Autism:** The Importance of Increasing Residential Supports

**Quotable**, from the Phantom Tollbooth

### **Calendar Reminders**

**Coming Up: New York:** [Hotline Nets Thousands Of Abuse Claims](#); **Wisconsin:** [Mother sues group home after daughter's death](#); and **Illinois:** [Judge puts some Murray Center residents under court-appointed guardian](#)

-----  
**1. Sharing our Success! In celebration of 30 years and new initiatives, VOR offers complimentary subscriptions**  
-----

August 9, 2013

Dear VOR Members and Advocates,

At its June 2013 Annual Board Meeting, the VOR Board of Directors discussed ways to celebrate VOR's 30th Anniversary and our new Quality in the Community Initiative. Sharing seemed the most appropriate way to celebrate and expand our advocacy to many more people.

In that spirit, VOR is pleased to announce the opportunity for

Speaking out for people with intellectual & developmental disabilities



[www.vor.net](http://www.vor.net)



/VOR



@VOR\_NET



[info@vor.net](mailto:info@vor.net)

**Reminders:  
Help VOR Grow!**

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

VOR.net:  
Your one-stop  
advocacy  
resource

non-members to receive a complimentary subscription to VOR's publications. Complimentary subscriptions to the Weekly E-News Update and The Voice newsletter will expire June 2015 and will only be available electronically.

A message for your use to share with your friends, family and other advocates (perhaps members of other organizations to which you belong) is below.

It is very important that VOR members, who are familiar with our good work and advocacy, help by spreading news of this exciting offer and encouraging everyone you know to sign up for a complimentary subscription to VOR.

This is a unique, one-time offer so please help is spread the word. As loyal members you are credible voices in support of the value of VOR's information and advocacy. With your help, we can expand our numbers and be that much more effective. Thank you!

**Julie Huso**  
Executive Director

**[Share this message with your friends](#)**

**Sharing Our Voice: Expanding Influence**  
**VOR Offers Free Complimentary Subscriptions for Limited Time!**

In celebration of VOR's 30th Anniversary and Quality in the Community Initiative, VOR would like to extend a complimentary subscription to you and members of any other organization who are not currently VOR members who are not currently VOR members and have a valid email address.

A complimentary subscription will allow you to receive VOR information and stay up-to date on what is happening in the developmental and intellectual disability community across the country.

This complimentary subscription will provide you electronic access to VOR's publications until June, 2015. The faster you sign up, the longer you will be able enjoy the benefits VOR provides.

All you have to do is send an email to [jhuso@vor.net](mailto:jhuso@vor.net), reference "Complimentary Subscription" and provide your name, address and email. It really is that easy. This information will NEVER be shared or sold!

So join us today and please share this great opportunity with your members, subscribers, friends, and family.

**2. Goodbves are never easv**

**Reminders:  
Help VOR Grow!**

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

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

-----  
It is with sadness that I share that long-time VOR volunteer, Barb Kolassa, passed away earlier this week after a lengthy illness. She was 81 years old.

Barb was recruited as a volunteer in the Rolling Meadows office nearly 15 years ago as part of the Retired Seniors Volunteer Program. In about 1999, she won RSVP Volunteer of the Year due to her efforts for VOR.

Barb assisted in all facets of the organization's office work, from stuffing envelopes to database management (entries and lists). It was the computer work she loved, and due to these skills, VOR continued to benefit from her good work and efforts even after the Rolling Meadows office closed. Barb welcomed Julie into her home during Julie's visits to Illinois and she continued to assist VOR for many years, up until the last 6 months when her health began to deteriorate. She helped Tamie format email lists and was especially helpful to Julie in pulling different database reports for her development work. For many years, Barb also received and collated the VOR proxies, helping VOR keep count and records during our Spring Board elections.

You can view [Barb's obituary](#) here and, if you knew her or just want to express your gratitude for her VOR contributions, you are encouraged to sign the guest book.

Barb was a good friend to VOR and will be sorely missed.  
Respectfully,

***Julie and Tamie***

***Supporting an array of housing options for people with autism, supporting choice***

**3. Designing a Community for Families Living with Autism:  
If you build it, we will come**

-----  
**Seattle Children's Hospital Autism Center \* Lynn Vigo,  
MSW, LICSW \* July 31, 2013**

As my child, and we, get older, I've been thinking a lot about our living arrangement in the future. I wrestle with wanting her to live with us forever but knowing we won't live forever. I see and feel the cumulative effect that years of care-giving, including regular, significant sleep deprivation, has had on us. I know that it would be good for her and us to have some separation, some distance, in the same way our son, who is going off to college in the Fall, will have.

In a perfect world, there would be many options from which a family could choose. But what I see "out there in the community" now is far from perfect with very few options available for a large group of soon-to-be young adults with

autism.

[Read more, comment and share](#)

#### **4. Will Government Limit a Spectrum of Housing Options for Autism?**

---

##### **Age of Autism \* July 2013 \* By Nancy Bernaitotis**

As is typical of our government, a ruling meant to protect Americans with disabilities (Olmstead v. L.C. 1999) is being misconstrued to the detriment of this population. In Olmstead v. L.C., a ruling requires states to “eliminate unnecessary segregation of persons with disabilities and to ensure that persons with disabilities receive services in the most integrated setting appropriate for their needs.”

In 2009, President Obama issued a proclamation launching the “Year of Community Living” and directed his Administration to redouble enforcement efforts.

The U.S. Senate committee on Health, Education, Labor, & Pensions (HELP) lead by Senator Tom Harkin (D-IA) is charged with this enforcement.

In May of 2013, Jeff Rosen, Chairperson of the National Council on Disability (NCD), an independent federal agency charged with advising Congress and the executive branch on disability policy, wrote a letter to Shaun Donovan, Secretary of the U.S. Department of Housing and Urban Development (HUD), interpreted the ruling to mean that individuals with disabilities move from provider-owned housing into their own homes or scattered-site housing and apartments, and urged HUD to issue “guidance to recipients of HUD funds on meeting the obligations of Olmstead and the integration mandate of the ADA.” In his letter, Mr. Rosen seeks to define community living as “utilizing a definition that excludes gated communities, segregated farmsteads, clusters of group homes, settings that restrict personal choice and control, and other settings with the characteristics of an institution.”

By creating that definition of community living, the NCD is reducing options for appropriate housing while the disability numbers are skyrocketing. There simply aren’t enough appropriate housing options or community supports to meet the needs.

[Read more, comment and share](#)

**Related news: [Rules limiting choice for Home and Community Based Services \[CMS-2249-P2\] still pending \(DD News Blog, July 2013\)](#)**

#### **5. Spotlight on National Association of Residential Providers for Adults with Autism (NARPPA): The Importance of Increasing Residential Supports**

-----  
**Autism Speaks \* August 5, 2013 \* by Leslie Long, Autism Speaks Director of Adult Services**

At Autism Speaks, we understand that there is a critical shortage of housing options for adults with autism and we want to listen to as many solutions and barriers as possible to help us understand the needs of the whole community. We are bound to groups like NARPAA to help solve the housing crisis. NARPAA represents support models across the country that range from supported living to rural, farmstead settings. The group comes together to meet once a year to share their wisdom and experience and we want to be at the table when they share promising practices and challenges.

[Read, Comment and Share](#)

**Quotable**

*"You must never feel badly about making mistakes," explained Reason quietly, "as long as you take the trouble to learn from them. For you often learn more by being wrong for the right reasons than you do by being right for the wrong reasons." ~ The Phantom Tollbooth*

=====

**Calendar Reminders:**

**\*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](#)**

**FREE WEBINAR:** How Congress Works: The Basics. Hosted by Peter Kinzler and Larry Innis.

**\* AHCA/NCAL to host Intellectual and Developmental Disabilities (ID/DD) Day – October 6, 2013. [Details online.](#)**

VOR  
836 S. Arlington Heights Rd., #351  
Elk Grove Village, IL 60007

Tel: (605) 399-1624  
Toll Free: (877) 399-4867  
Fax: (605) 399-1631  
Email: [info@vor.net](mailto:info@vor.net)

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

---

If you no longer wish to receive these emails, please reply to this message with "Unsubscribe" in the subject line or simply click on the following link: [Unsubscribe](#)

[Click here](#) to forward this email to a friend

VOR  
836 S. Arlington Heights Rd.  
#351  
Elk Grove Village, Illinois 60007  
US

[Read](#) the VerticalResponse marketing policy.