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November 21, 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

#GIVINGTUESDAY™

**Generosity. Volunteering. Awareness.
Donations.**

"A thankful heart is not only the greatest virtue, but the parent of all the other virtues." ~ Cicero

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VOR and YOU

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Thank you for
your 2014 year
end donation.

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VOR and YOU

1. You have 1.5 million choices. [We are very grateful you chose VOR.](#)

According to the Foundation Center, there are 1.5 million nonprofit (501(c)(3)) organizations.

Yet, VOR is different than all the rest.

VOR is the **ONLY** national 501(c)(3) advocacy organization for people with disabilities that supports a full array of residential, employment and education options for people with intellectual and developmental disabilities.

We expressly **OPPOSE** “**deinstitutionalization**”: the downsizing, reduction and elimination of specialized residential facility care, workshop employment, and education options without regard to individual need, demand and choice.

We express **SUPPORT CHOICE** and the expansion of

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high**QUALITY** residential, employment and education options in small and large settings to accommodate the vast continuum of individualized need.

We know you have 1.5 million other choices.

[Thank you for choosing to support VOR with your membership support \(some members for years and even decades!\) and for your charitable giving this Holiday season.](#)

2. Interested in ordering “*Gloria Goldfish Lose a Loved One*”? Author Sally Chappell offers to donate portion of sales to VOR

Last week, we shared that long-time VOR member and accomplished author had published her first children’s book. “Gloria Goldfish Loses a Loved One” aims to help individuals with intellectual disability, children and others to cope with the loss of a parent, loved one or friend.

The book is now available for sale and Sally has generously offered to donate a percentage of the sales to VOR.

To order “Gloria Goldfish Loses a Loved One,” send \$10 to Sally Chappell/Stickywikitt Press at address below along with your name and address:

Sally Chappell
Stickywikitt Press
3750 N. Lake Shore Dr. Suite 10D
Chicago, IL 60613

Thank you!

3. Speakers announced for VOR’s 2015 Annual Conference

VOR’s 2015 Annual Conference, “Advocating for Choice by Expanding Opportunities,” will be held on Sunday, June 7, 2015 in Washington, D.C.

Speakers will focus on an advocate’s role in making residential and employment choice a reality by expanding opportunities according to individual need.

Confirmed speakers are:

- **Terry Farmer**, Executive Director of ACCSES, which represents “more than 1,200 disability service providers across the country as the Voice of Disability Service Providers”;
- **Lois Sheaffer-Kramer**, Director of Government Relations and Community Support for Marklund a

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private intermediate care facility in Geneva, Illinois, and Coordinator of Respite Education & Support Tools (REST), a nationally-recognized train-the-trainer program that equips volunteers with the skills needed to support caregivers in their community through respite.

- **Scott Osterfeld**, an Outreach Coordinator for Butler County Board of Developmental Disabilities and the President of Osterfeld Consulting, a principle-based educational and consulting company that provides education and training in the human service field. His keynote presentation is titled, "A Bear Can't DANCE while Hibernating."

In addition, VOR will host its annual legislative briefing to prepare participants for visits to Congress, beginning June 8, 2015.

[Registration details and agenda details will be provided after January 1, 2015 on VOR's website.](#)

Mark your calendars!

4. Misericordia's Sister Rosemary Honored as a Chicagoan of the Year 2014

Chicago Magazine (November 18, 2014) has selected Sister Rosemary Connelly, the executive director of Misericordia for its list of 2014 Chicagoans of the Year for her compassionate and extraordinary work on behalf of people with intellectual and developmental disabilities.

VOR extends our warm congratulations for this deserving honor. VOR is honored to have joined Sr. Rosemary and the Misericordia family for a small part of her decades-long mission of offering people with developmental disabilities a "life worth living." We know first-hand the extraordinary joy and comfort Sr. Rosemary has personally brought to those in her care and to their families.

[Watch the video here](#)

5. VOR's Wyoming State Coordinator Blog: "Has Deinstitutionalization Failed?"

Wyoming DD News Blog * November 11, 2014 * by Shawn Humberson, VOR Wyoming Co-State Coordinator

Summary: At a recent Facilities Task Force Meeting, Senator James Anderson. Senate District 28. posed

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the question, "Has deinstitutionalization failed?" Yes, Senator Anderson, deinstitutionalization has failed.

Deinstitutionalization

In the 1980's, Senator John Chafee (R., RI) introduced legislation that would have defunded Medicaid Intermediate Care Facilities (ICFs). Since then, the push to de-institutionalize has gained momentum. As of 2011, twelve states had no large ICFs; AL, AK, DC, HI, MI, MN, NH, NM, OR, RI, VT, WV; and three states had no ICF of any size; AK, MI, and OR.

Today, despite the objections of guardians and advocates, many states are closing or redefining their ICFs; forcing individuals from their homes and into community services or leaving them without services. Nationally, there are 317,000 individuals on waiting lists for Medicaid Waiver services. There seems to be a direct correlation between deinstitutionalization and waiting list numbers. Alabama requires capacity to grow by 69.3% to meet needs. Alaska requires 50.3%, New Mexico requires 144.4%, and West Virginia requires 114.4% growth in capacity. 853,000 persons are living with caregivers age 60 or older.

Community Tragedies

"Community tragedies are widespread and now well-publicized. The stories are haunting and made all the more tragic and unacceptable given just how predictable they have become," **Tamie Hopp, VOR.**

Georgia has aggressively deinstitutionalized and transitioned individuals from facilities to community settings.

[Read more, comment and share](#)

STATE NEWS

6. Nebraska: Sparking a Flame

Beatrice Daily Sun * November 20, 2014

The Big Blue Candle Co. is the new kid on the 600 block of Court Street, but the specialty store is out to make its mark with specialty candles, candy and gifts.

And the company is getting some extra help from residents of Beatrice State Developmental Center, who do everything from make to sell the varieties of candles.

The store is operated by Integrated Life Choices, a Lincoln-based group aiming to give people with disabilities the opportunity to lead a fulfilling life.

Operated as a partnership between the group and Beatrice State Developmental Center, ILC vocational manager Jackie Barber said the store gives BSDC residents a chance to gain real-world experience in the workforce.

“They like the social interaction of meeting new people and love to show people around and show them what we have,” Barber said. “They work the cash register so it’s a learning experience.

[Read more, comment and share](#)

7. Wisconsin: Mondays with Mike - Handle with care

Safe & Sound Blog * October 20, 2014 * by Mike Knezovich

We were back in Wisconsin again this past Saturday, this time to visit our son Gus, and for me, to attend a meeting of the Bethesda Parent Guardian League. The League is exactly as its name implies — parents and guardians of developmentally disabled people served by Bethesda Lutheran Communities. I’ve been on the board of the League for about 10 years now.

The League’s members meet regularly to get updates from Bethesda Staff and present our concerns about how our people are doing. Maybe most important: we get to share company with people who know. Know what it’s like to have children and siblings and loved ones who have developmental — and typically also physical — disabilities. We don’t have to explain fundamental things to one another. We can look into each others’ eyes sometimes and just nod. It’s kind of priceless.

For the past 10 years or so, Bethesda has been

negotiating and navigating the community placement movement. In short, there has been a national effort toward downsizing and eliminating large, standalone institutions in favor of group homes in community settings. Bethesda's campus once was the home for hundreds of residents. I can't recall precisely how many were living there when Gus moved there in 2002, but I think it was around 175. It's been shrinking — by state mandate — ever since.

[Read more, PLEASE COMMENT, and share](#)

SPECIAL EDUCATION NEWS

8. Special Education: Schools Must Offer Communication Supports, Feds Say

Disability Scoop * November 14, 2014

In [guidance](#) issued Wednesday, federal officials said the nation's public schools have obligations under three separate laws to "ensure that communication with students with hearing, vision and speech disabilities is as effective as communication with all other students."

While requirements under the Individuals with Disabilities Education Act, Americans with Disabilities Act and Section 504 of the Rehabilitation Act vary, schools must comply with all three laws to meet individual needs. That can mean providing assistance ranging from communication boards or Braille materials to sign-language interpreter services and portable speech-generating devices, according to documents sent jointly from the U.S. Department of Education and the U.S. Department of Justice.

In cases where assistance is needed, schools should give "primary consideration to students and parents in determining which auxiliary aids and services are necessary to provide such effective communication," the federal guidance said.

Nonetheless, schools are not required to provide anything more than is needed to "ensure effective communication," officials indicated.

The guidance comes in response to a federal court decision last year in a case known as *K.M. v. Tustin Unified School District* which clarified schools'

obligations under the various laws when addressing students' communication needs.

[Read more, comment and share](#)

9. Wisconsin: Suit alleges schools violating disability law

Pioneer Press * November 19, 2014

Three families of children with disabilities argue in a federal lawsuit that Wisconsin's open enrollment program is unconstitutional because school districts can reject students with disabilities while accepting others.

The lawsuit, filed Tuesday in U.S. District Court in Madison, also argues that it's discriminatory for schools to set quotas for how many students, both with disabilities and without, they will accept under open enrollment every year.

The law requiring that districts determine the number of both regular and special education spaces available for open enrollment was passed by the Republican-controlled Legislature and signed by Gov. Scott Walker in 2011. It took effect in 2012.

The families bringing the lawsuit are asking that the law be declared unconstitutional; that schools be prevented from enforcing it; and for unspecified damages to be paid.

[Read more, comment and share](#)

10. Louisiana: Are New Orleans Schools Failing Students With Disabilities?

NPR Morning Edition * November 20, 2014

In New Orleans, schools have long struggled to provide for students with physical, emotional and mental disabilities. Even before Hurricane Katrina, many parents had to fight for extra help. But many say things have only gotten harder since the city's public school district shifted almost entirely to charter schools.

[Read more, comment and share](#)

[Listen to the Story](#)

RESEARCH NEWS

11. Autism's Gut-Brain Connection

National Geographic * November 14, 2014

The different gut bacteria in autistic individuals may be contributing to the disorder.

[Read more, comment and share](#)

Quotable

"Not speaking up has too long left state decision-makers believe their past actions are OK with everyone affected." ~ Mary Reese, VOR Board Member

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Calendar Reminders:

Tuesday, December 2, 2014:

#GivingTuesday

<http://vor.net/donate-now>

Tuesday, March 24, 2015:

[American Health Care Association ID/DD](#)

[Washington Fly-In](#)

Congressional speakers are being invited, a legislative update will be provided, and Hill visits will follow in the afternoon. Breakfast and a boxed lunch will be provided to you. [Registration is free but required.](#) VOR members are encouraged to attend.

Sunday, June 7, 2015:

VOR Annual Conference: ADVOCATING FOR CHOICE BY EXPANDING OPPORTUNITIES. [Speakers](#)

[Announced. Registration details coming soon. Check](#)

[VOR's website often for updates.](#)

Archives:

* Thursday, March 20, 2014

[VOR's "Regional Meetings: The Need for Advocates to Act Global and Local" Webinar.](#)

***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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