



Speaking out for people with intellectual and developmental disabilities



www.vor.net



/VOR



@VOR_NET



info@vor.net

Reminders: Help VOR Grow!

Challenge!
Recruit 5 New
VOR Members
Today!

Celebrating
Home: Holiday
Shop and
Benefit VOR

Make a Lasting
Impact with a
Will Bequest

VOR Media Action Alert

VOR Weekly News Update, October 19, 2012

Table of Contents

Media Action Alert

1) Introduction: Opportunities to use our voices to influence the media
2) ***The Washington Post***: “My son is schizophrenic. The ‘reforms’ that I worked for have worsened his life.”

- The Article
- How to Comment
- VOR’s Comment

3) ***NPR***: “Disabled Kids Living Isolated Lives In Institutions”

- The Article
- How to Comment
- VOR’s Comment

4) ***The New York Times***: After Decades in Institutions, a Bumpy Journey to a New Life

- VOR’s Letter to the Editor

Media Action Alert

1) Introduction: Opportunities to use our voices to influence the media

Whether the media gets a story right or wrong, any media attention on issues impacting individuals with intellectual and developmental disabilities (I/DD) and their families provides choice advocates an opportunity to speak out.

This *VOR Weekly News Update* doubles as a Media Action Alert. Two news items are shared and both require our attention. Please follow the links below to submit online comments. VOR’s comments in response to these articles are also shared.

2) **“My son is schizophrenic. The ‘reforms’ that I worked for have worsened his life.”**

The Washington Post * October 15, 2012 (Editorial

VOR
Awareness
Event

VOR.net:
Your one-stop
advocacy
resource

by Paul Gionfriddo)

Tim is homeless. But when he was a toddler, my colleagues in the Connecticut state legislature couldn't get enough of cuddling him. Yet it's the policies of my generation of policymakers that put that formerly adorable toddler — now a troubled 6-foot-5 adult — on the street. And unless something changes, the policies of today's generation of policymakers will keep him there.

[Read More](#)

How to Comment: Go to the “blue bar” which says “View all comments” and select “Add your comment.” You will be asked to sign in. Registration is free)

VOR Comment (posted under VOR4Choice)

Families of individuals with intellectual disabilities (I/DD) can relate to Tim's story. An important difference is that Tim's father, Mr. Gionfriddo, admirably admits his wrong. Families of ID/DD can only hope that that advozealots spending so much money and energy on displacing their loved ones from specialized facilities will benefit from Mr. Gionfriddo's 20/20 hindsight. Parallel to the advocacy which closed so many mental health facilities, advocacy is now directed at people with I/DD and closing their specialized homes. Not surprisingly, many very fragile people with I/DD – vulnerable like Tim but for whom death, abuse and neglect (not homelessness) are the feared outcomes – are being harmed. This is not a big secret. The *Washington Post's* Katherine Boo won a Pulitzer for her “Invisible Lives” and “Invisible Deaths” series in 1999 and 2000; the *Post* has been reporting on the plight of the disabled in the District ever since. Earlier this year, the *New York Times* reported news of 1,200 “unknown and unnatural deaths” over ten years, as part of its “Abused and Used” series. Yet. pro-closure advocates – often federally-

funded lawyers and advocates – persist, blind or unconcerned to reality that a great many people are suffering and those whose voices matter most (individuals and their families) are pleading for a moratorium on a wrong-headed, inhumane deinstitutionalization policy. See, www.vor.net for more information.

3) [“Disabled Kids Living Isolated Lives In Institutions”](#)

National Public Radio * *Neal Conan's Talk of the Nation* * October 16, 2012

Thousands of children with physical and mental disabilities live in institutions, isolated from their families and decades younger than other patients. The institutions are often better equipped to handle their medical needs, but can fall short when it comes to other aspects of the kids' lives.

[Read Transcript or Listen to radio show here](#)

[How to Comment:](#) Go to the end of the article. You must register. Registration is free.

VOR's Comment (Posted as Tamie Hopp)

Neal Conan's Talk of the Nation's feature on children in nursing homes was uncharacteristically biased.

Rather than provide a balanced perspective of the range of care options needed by profoundly disabled children and adults, his guest, Joe Shapiro, led listeners to believe that no disabled person is well-served in any “institutional” setting.

Such a “broad brush” approach doesn't work with a population as diverse as people with disabilities. Policies that promote such simplistic “solutions” – “close all institutions!” – have led to well-documented, dangerous outcomes for very fragile Americans.

The disabled population is incredibly diverse, a reality that has been ignored by NPR's features on nursing homes. There are individuals who have no apparent disability to

individuals with complex medical needs or extreme behaviors with the cognitive abilities of infants.

Residential programs for people with severe disabilities are also numerous. There are federally licensed nursing homes, specialized nursing facilities for people with intellectual and developmental disabilities (NFs/DD) and intermediate care facilities (ICFs/MR) for people with I/DD.

As a society, we celebrate diversity and individual choice. Many individuals with profound intellectual disabilities and their families choose specialized facility-based care (ICFs/MR and nursing facilities).

We don't judge seniors or college students for cost effective, "congregate" options. We don't fault the health care industry for offering a range of treatment settings based on need and choice.

To suggest, as NPR has done, that every disabled individual is better served in smaller, non-"institutional" settings is unenlightened, careless journalism, and potentially dangerous. All needs cannot be safely met in smaller, unlicensed settings.

Advocates, including some federally-funded organizations, do not see this logic and continue to aggressively pursue deinstitutionalization – the closure of all "institutions" – without any regard for well-documented and predictable tragedies. Mr. Conan is challenged to offer the opposing perspective in his usually well-balanced Talk of the Nation series. NPR, with its one-sided reporting on this issue, has only added fuel to the fire and put a great many fragile people at risk.

4) [The New York Times: After Decades in Institutions, a Bumpy Journey to a New Life](#)

The New York Times * September 29, 2012

Here in Georgia, about 360 developmentally disabled patients have left state hospitals over the past two years, health officials say, moving mostly into small group homes that house four people each. About 400 more will leave over the next three years, nearly emptying the state's institutions of people with severe mental disabilities, autism and dementia.

[Read More](#)

VOR's Letter to the Editor (submitted Oct. 4, 2012)

Mortality, isolation, abuse and neglect. This is the underbelly of deinstitutionalization, as reported by the New York Times, other media from around the country, and court monitor reports. ("A Bumpy Journey," Sept. 29).

It's no wonder that the transition has "been fraught with anxiety." The community is simply not ready and families find little solace in saying "I told you so."

Federal law rightly recognizes that families of individuals who have the cognitive abilities of infants are the most informed advocates and that choice must be respected, yet the Justice Department routinely excludes them.

While families are pleased that some individuals have found success in smaller settings, this success need not come at the expense of the vast majority of individuals who didn't want to move in the first place.

The Justice Department, which should know better, is blinded by ideology, ignoring the law, common-sense and predictable tragedies.

Ann S. Knighton

Ms. Knighton is the President of VOR, a national organization advocating for high quality care and human rights of intellectual and developmental disabilities. She is also the President of the East Central Georgia Regional Center, where her daughter, Erica, is a resident.

Tel: (605) 399-1624
Toll Free: (877) 399-4867
Fax: (605) 399-1631
Email: 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.

