December 6, 2013

VOR Weekly News Update

News and views for VOR Advocates

About VOR * ***Refer a Friend*** * ***Donate***

Speaking out for people with intellectual & developmental disabilities

www.vor.net

/VOR

@VOR_NET

VOR4Choice

info@vor.net

Reminders:
Help VOR Grow!

Table of Contents

Celebrating Home: Holiday Shop and Benefit VOR

About VOR

Make a Lasting Impact with a Will Bequest

VOR.net: Your one-stop advocacy resource

10. Kansas: A Fight Over Developmentally Disabled Shifting To Medicaid Managed Care

11. Illinois: Marklund expansion aimed at helping more kids with autism

***Quotable*, by Nelson Mandela**
Calendar Reminders

VOR and You

1. Dan Torisky, Long time VOR Member and Pennsylvania Advocate, Offers Tribute to Polly Spare, VOR

Letter from Daniel A. Torisky, President of the Autism Society of Pittsburgh * September 11, 2013 (reprinted with permission)

Read original letter online

September 11, 2013

Ms. Ann Knighton, President
VOR
Suite 251
836 S. Arlington Heights Road
Elk Grove Village, IL 60007

Dear Ms. Knighton,

We are all so pleased to see that Polly Spare is your 2013 Voice Award recipient. No matter how one might praise Polly and her work, it would be an understatement. Her energy and her impact in addressing critical issues involving those who do not chose to be care-dependent are unmatched.

In Pennsylvania, she often stood alone against the statist-driven mindset of our state's governors, human service bureaucrats, and their "advisory committees" dominated by one-size-fits-all advozealots. Polly's example continues to inspire us parents and families as we battle to protect our right to learn about and then choose options we feel are best for our sons and daughters with mental retardation, autism and related disorders of behavior and communication.

Particularly memorable was Polly's exhaustive 24/7 support in the defense of the Western Center state residential care and treatment facility against the 12-year assault by the combined forces of Pennsylvania's Association for Retarded Citizens, its Protection and Advocacy Agency, its Department of Public Welfare Secretary Feather Houstoun and Deputy Nancy Thaler, and its Governor Tom Ridge.

This fight was lost in 2001 partly due to overwhelming state funding, but primarily due to the untimely death of our magnificent attorney William Burke, another most deserving VOR Award recipient.

Polly Spare and all of us will always grieve the resultant deaths of 38 former Western Center residents, uninvestigated, during and soon after the brutal closing process. Only God knows how many more have left this earth prematurely due to theses statists, as well as the thousands more languishing on waiting lists, in unstable homes, prisons, mental health units, tent cities and under bridges.

Thanks to organizations like VOR, the nationwide battle against this inhuman, anti-family scourge is still not lost. And, I am personally grateful to have been on this earth the same time as all of you - and Polly Spare.

Daniel A. Torisky
President, Autism Society of Pittsburgh
Secretary, Autism Society of Pennsylvania
Past President, Autism Society of America
Past President, Western Center Board of Trustees

cc: Polly Spare
Tamie Hopp

Reminders:
Help VOR Grow!

Celebrating Home: Holiday Shop and Benefit VOR

About VOR

Make a Lasting Impact with a Will Bequest

VOR.net: Your one-stop advocacy resource

Read original letter online

2. A 'thank you' from Patrick Costa, longtime resident of Fernald Developmental Center

----

COFAR Blog *** December 5, 2013 * by Ann Witham**

A funeral mass was held November 26 for Patrick Costa, a longtime resident of the Fernald Developmental Center, who died on November 19 at the age of 49. Below is a touching letter written in Patrick's voice by his guardian, Ann Witham, who read it at the mass for Patrick. Ann is a former Fernald employee who agreed to be Patrick's guardian after his mother died. She also managed the Fernald chapel for the Rev. Bill Leonard, who has been the pastor at St. Jude Parish in Waltham in addition to his Fernald Chaplin duties.

My Dear Family and Friends,

During my time on earth, I could not talk; I never learned how to read or write or spell; or how to type or use a computer. But my life has changed. I'm with God now and as long as He's ok with it, I can do almost anything, including writing this thank you letter.

The first thing I want to say is a big thank you to all the folks at Fernald for caring for me for almost forty years. They gave me the best they could and I am truly grateful for their efforts.

Read more, comment and share

Advocacy Perspectives

3. The Future of People with Severe Mental Illnesses is in the Wrong Hands

----

The Huffington Post * December 3, 2013 * By Susan Inman

Attn VOR Advocates*:* *This relates to advocacy for* *people with mental illness, but the concerns sound all too familiar: The over-reach of "we know better" federally funded advocates and agencies pretending that every person with mental illness can and must receive the same services. VOR writes about this concern, relative to people with intellectual and developmental disabilities, in its article, "When Equitable Does Not Mean Equal: Respecting Diversity and Choice: VOR presents its Key Principles in Support of Ensuring the Rights and Opportunities for All People with Disabilities. The organization calls on the broader community of advocates to support and promote these principles," EP (Exceptional Parent) Magazine, October 2013*

The Future of People with Severe Mental Illnesses is in the Wrong Hands

By Susan Inman

Excerpts

Organizations have become skillful at lobbying for humane supports for people with most disabilities.

To understand the problem, look at the taxpayer-funded Alternatives conference being held this week in Austin, Texas.

Not only will you not find references to the most severe illnesses, you won't find sessions on the issues that are most important to the well-being of this population. There is certainly nothing about improving the public education campaigns about mental illnesses so that people can receive appropriate help earlier. Nor is there anything about advocating for cognitive remediation programs, even though it is usually these problems that lead to disabilities for people with schizophrenia. Similarly, there is nothing about the educational supports and accommodations available for people with diagnosed disorders.

As well, there is nothing in the four day conference about getting the mental health system to better collaborate with family caregivers whom many adults living with schizophrenia rely on for daily assistance. "Family caregivers" is another absent term, since the consumers (of mental health services) who attend this conference are quite capable of taking care of themselves. In fact, sessions at this conference help train participants to increase their power within the mental health system to deliver mental health care to others.

That aspect of this conference came under close scrutiny last spring when [a U.S. Congressional Subcommittee began investigating the policies of the U.S. Substance Abuse and Mental Health Services Administration (SAMHSA)](), which is the major funder of the Alternatives conference. Committee members wanted SAMHSA Director Pamela Hyde to justify sponsoring a conference that actively encourages people to stop medications; the response was that SAMHSA funds many events.

Read more, comment and share

4. When does "choice" mean "restriction"

--

***Because We Care- Beyond Inclusion* * December 1, 2013 * by Cheryl Felak**

Many things are changing in the name of "choice" but is this all really choice or is it putting more restrictions on people?

By micromanaging definition of words such as "community" and "employment" our government and advocates are actually reducing the alternatives by creating restrictions on how funds are spent. Reducing alternatives which greatly benefit many of our loved ones means they lose the ability to make choices.

Having these strings attached to federal funds, funds which are critical to our most vulnerable citizens, forces them into situations

Celebrating Home: Holiday Shop and Benefit VOR

About VOR

Make a Lasting Impact with a Will Bequest

VOR.net: Your one-stop advocacy resource

which may not be in their best interest. Is this what choice and alternatives are about?

The fact of the matter is that many do want to live in community settings with similar people, share supports and be able to walk independently outside their home to a friends, an event, or to shop. The other fact is that by eliminating “sheltered workshops”, without replacing with an alternative, forces the people who work in those jobs to be shuttered away in a home, isolated from their community. Is this what choice is about?

Chris Collins, R-Clarence, represents the House of Representatives’ 27th District, which includes about half of Ontario County, New York, writes about this issue with regards to sheltered workshops.

“The federal government is not in a position to direct all disabled people to join competitive employment. Ultimately, the choice to stay in a workshop should be an employment option for the disabled who are not yet ready to make their transition to a competitive environment. Parents and providers are concerned about finding jobs in this tough economy, especially when non-disabled unemployment rates remain high and stagnant.” (Read more)

“Choice of employment” in this situation means the choice to not work since in reality many of these people would be unemployable in a competitive employment market. There are not enough funds to provide the needed support for these folks to hold a job in a competitive job market and the reality of the situation is these folks will be left with nothing – is that choice?

Please support real choice and real alternatives!

Read more, comment and share

State News

5. Tennessee: 21-year-old lawsuit over institution for intellectually disabled reaches end

---

The Tennessean * December 5, 2013

A decades-old lawsuit over conditions at a West Tennessee institution for people with intellectual disabilities has been dismissed, after a federal judge found the state met court-ordered improvements.

The original lawsuit, relating to the Arlington Development Center in Memphis was filed in 1992 by the U.S. Department of Justice. People First of Tennessee, a group run by and for people with disabilities, filed a separate lawsuit.

On Wednesday, U.S. District Judge Jon McCalla ruled the state had complied with all conditions of a negotiated plan to end the lawsuit.

All residents of the Arlington facility were moved to other locations by 2010, but the lawsuit continued over a series of other disagreements between the state, the Justice Department and disability rights groups, including the treatment and welfare of residents in their new homes.

A separate lawsuit by the U.S. Justice Department and People First involving other state-run facilities for people with intellectual disabilities in Nashville and east Tennessee has not yet been resolved.

In 1996, Tennessee officials agreed to settle the lawsuit against Clover Bottom Development Center and the Harold Jordan Center in Nashville, and the Greene Valley Developmental Center in Greeneville. The settlement agreement also set out certain conditions that the state is still working to meet.

The state agreed to move all residents from Clover Bottom by 2010. While many have been moved to new homes or facilities, nearly 40 residents still remain.

The Arlington lawsuit alone has cost the state more than $239 million since it was first filed. That total includes $158 million in additional or improved services to people with disabilities required by the court agreement.

Read more, comment and share

6. Massachusetts: DDS challenge to mother's guardianship of her son dismissed

--

COFAR Blog * November 25, 2013

The mother of an intellectually disabled man, who has been locked in a dispute with the Department of Developmental Services for several years over her son's medical needs, will be able to remain as his guardian, according to a probate court agreement reached last week.

A Middlesex County Probate Court judge last week signed off on the dismissal of a year-long effort by the DDS to remove Patricia Feeley as guardian of her 27-year-old son, Michael. DDS had filed a petition in probate court in November 2012 to appoint James Feld, an attorney, as Michael's guardian, even though Feld had never met Michael.

The DDS's long-running dispute with Feeley, a COFAR Board member, has centered around Feeley's contention that Michael, who has type 1 diabetes, needs a residential care setting with 24-hour nursing. Feeley has been trying for years to find a suitable residential placement for her son, who has lived at home his entire life. DDS has taken the position that Michael doesn't need round-the-clock nursing.

Read more, comment and share

7. Massachusetts: Family is shut out of contact with special needs daughter

--

Cofar blog * December 6, 2013

Maryann Duzan and other members of her family lost their guardianship of Maryann's intellectually disabled daughter, Sara, in 2009, based on an admission by Maryann that she once slapped her daughter on the cheek, and the apparent perception that the family has been too aggressive in advocating for her.

As a result, a series of increasingly restrictive limits has been placed by court-appointed guardians and residential providers on family communication with Sara. Since June, the family has not been allowed to see Sara, who is currently living in a group residence in Westminster, MA, run by a state-funded, corporate provider.

As of late November, the family was prohibited even from talking with Sara over the phone. The family is afraid she is being subjected to what they consider abusive "restraints" by the group residence staff, but they have no way of determining what is actually going on.

Maryann contends her daughter, who is now 22, has been kept a virtual prisoner in the residence run by Becket Family of Services since late July. Sara has a condition known as Smith Magenis Syndrome, a genetic disorder characterized by intellectual disability and behavioral outbursts. The family maintains that the use of restraints to control those behaviors actually makes them worse.

Read more, comment and share

8. Washington State: Feds: DSHS neglected disabled to cut costs, may owe $16M

***Seattle Times* * November 22, 2013**

A federal review has determined Washington broke the law repeatedly by denying therapy, recreation, personal-care training and other required services to 27 developmentally disabled residents at Spokane County's Lakeland Village.

The state could face a penalty of up to $16 million.

Read more, comment and share

9. California: Task force on future of Sonoma Developmental Center (SDC) nears completion

---

***Kenwood Press* * December 1, 2013**

The future of the Sonoma Developmental Center (SDC) remains uncertain as a group tasked with working up a scenario for the long term care of California's severely developmentally disabled population nears completion of that assignment.

The Task Force on the future of the State Developmental Centers will have its final meeting on Dec. 13 in Sacramento. After that, the California Health and Human Services Agency (CHHS) will decide whether to phase out all or some of its five existing centers, perhaps modifying some of the existing centers, such as Sonoma's, to provide the care required for the most vulnerable and medically fragile patients who cannot be adequately housed in community settings.

Kathleen Miller, president of the Parent Hospital Association at SDC and the mother of a resident there, is a member of the task force. She sees an uphill fight to keep the existing facility intact, although what the final changes might be, no one yet knows.

Read more, comment and share

10. Kansas: A Fight Over Developmentally Disabled Shifting To Medicaid Managed Care

--

***Kaiser Health News* (in collaboration with the*Washington Post*) * December 5, 2013**

Aldona and Pat Carney call their son, Neil, "a 24-7 kid." He's profoundly autistic, severely mentally retarded and attends a special school. He has tried to eat light bulbs and charcoal briquettes and can be aggressive, sometimes scratching people near him.

Neil, 18, who walks with a limp and carries around a grey sock that calms him, lives in a beige single-family home with a professional caregiver who’s known him for years. The house is equipped with cameras to track his movements and a backyard swing he loves to ride.

Neil Carney, 18, who is autistic and mentally retarded, enjoys a swing in the backyard of a house where he lives with a professional caregiver (Photo by Jenni Bergal).

Come January, the Carneys – and thousands of parents and relatives of developmentally disabled Kansans – fear that the world their loved ones have become accustomed to may turn topsy-turvy.

That’s when Kansas’ Medicaid managed care system – called KanCare — will take charge of all home and community-based services for about 8,500 developmentally disabled people, most of them adults. What concerns families and advocates the most is that the three for-profit national insurance companies that run KanCare will be responsible for a statewide program that they’ve never managed in Kansas or elsewhere. They’re also worried that the need to make a profit ultimately will destroy a system families and advocates think works well.

While Kansas will become the first state to make such a leap, it is being watched closely elsewhere, as at least two other states – Louisiana and New Hampshire – are considering moving in the same direction.

“This is an unprecedented model. No state has ever taken a developmental disability population and placed it in an arrangement like this, with an out-of-state managed care system, all at once,” said Rocky Nichols, executive director of the Disability Rights Center of Kansas, a legal advocacy group. “It’s almost like throwing everyone into the deep end of the pool."

By next year, more than two dozen states are expected to have set up programs to transfer frail elderly, mentally ill or physically disabled people into managed care for home and community-based services. But in most states, the developmentally disabled – people with impairments such as cerebral palsy, Down syndrome and autism – have been excluded from managed care for these services because their needs are so specialized.

Only a handful of states, including Michigan and Vermont, have moved the developmentally disabled into managed care for long-term services. They've mostly relied on existing networks of community-based nonprofits or county agencies or have made themselves the managed care organization. None has turned exclusively to national managed care companies, as Kansas is poised to do.

Read more, comment and share

11. Illinois: Marklund expansion aimed at helping more kids with autism

---

***Daily Herald* (NW Chicago-area) * December 2, 2013**

Shellise Janus tried to have her son with Down syndrome and autism attend public school.

But by the time Jordan Janus was a third-grader, it became clear to his mother that a traditional classroom wasn't appropriate for him.

"Jordan has pretty moderate to severe autism," the Carpentersville mother said. "It was just more than they (his former teachers) could handle. He was in a classroom with nine children and they had four aides in there. And it was still unmanageable for them."

She says Jordan needed more intensive and focused attention. Community Unit District 300 agreed to enroll him in a special school.

Now at 13, the youngster is attending Marklund's Life Skills Academy in Bloomingdale.

Shellise Janus says the school, which provides specialized support to students diagnosed on the autism spectrum, has been "a good fit" for her son.

So it comes as no surprise that she and other parents say they're thrilled about Marklund's plans to spend $4 million to construct a nearly 12,000-square-foot addition. The structure would allow Marklund to expand the Life Skills Academy.

Read more, comment and share
Watch video

Quotable
***"I am not a saint, unless you think of a saint as a sinner who keeps on trying."* ~ Nelson Mandela**

==================
Calendar Reminders:
Tuesday, March 25, 2014
AHCA/NCAL's fifth annual "ID/DD Residential Services Providers Hill Fly-In." Questions? Dana Halvorson, dhalvorson@ahca.org.

June 8, 2014
VOR 2014 Annual Conference and Initiative: *"Making it Happen: Reforming Policy and Law in Support of Person-Centered Quality and Choice"; Hyatt Regency, Washington, D.C.* **Details coming soon**

Week of June 9, 2013
VOR 2014 Congressional Initiative: Families and advocates visit Capitol Hill. **Details coming soon**

Sunday, October 5, 2014
American Health Care Association's 2014 ID/DD

Residential Services Day during AHCA/NCAL's 65th Annual Convention & Expo at the Gaylord National Harbor just outside of Washington, DC. Registration will open in Spring 2014.

Archives

***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.

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

JOIN VOR. DONATE TO VOR. MAKE A DIFFERENCE
