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February 3, 2012

VOR Weekly News Update

News and views for VOR advocates

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VOR and YOU

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Questions?

Contact Tamie Hopp at thopp@vor.net or 877-399-4867

2. VOR and 92 families file *Amicus Brief* in Pennsylvania case; ask court to overturn settlement

VOR and 92 individuals filed an *Amicus Curiae* brief in support of nine appellants (families of Pennsylvania's ICFs/MR), seeking to overturn a class action settlement initiated by five named plaintiffs (represented by Protection & Advocacy) and the State of Pennsylvania. The case is *Benjamin v. Pennsylvania Department of Welfare*.

The named plaintiffs in this action seek to transition from ICFs/MR to smaller community-based residences. Appellants and VOR did not oppose their right to do so. Rather, the appellants and VOR oppose the plaintiffs' attempt to impose their choices on appellants through a settlement and broadly defined class of individuals that includes all residents with profound intellectual disabilities who are unable to articulate their opposition to being moved. The Court granted class certification in the face of no opposition by the Pennsylvania Department of Welfare. The appellants' and VOR's concerns with this settlement are two-fold: (1) residents with profound intellectual disabilities often cannot get the care they need from the smaller residences; and (2) implementation of the settlement could so significantly depopulate the centers as to render ultimate closure inevitable. In fact, such transfers have already resulted in ICF/MR closures elsewhere and will likely do so in Pennsylvania as well. Even the District Court, in its decision approving the settlement, expressed concern about the problematic provisions which interpret silence as consent.

Specifically, VOR argued that the District Court's ruling to certify the class was at odds with the Supreme Court of the United States' ruling in *Olmstead v. L.C.*, which supported the right of individuals to choose a residential setting according to need. "The solution is not to move everyone from one type of facility to another. This is not only in direct contravention of *Olmstead*, but will cause unspeakable harm to those in need of institutional care." VOR is represented by attorneys Lesli Esposito, Nancy Rappaport and Jill Czeschin, of DLA Piper (Philadelphia). VOR's brief, filed December 27, 2011, was the second *Amicus Curiae* brief in this case in support of ICF/MR

residents and their families. The first, filed in August 2010, supported the efforts of families to intervene in the case. The December 2011 *Amicus Curaie* brief is available on VOR's [website](#); the August 2010 brief will be posted shortly.

3. Correction: Stephanie Vance's free chat hour is February 8 at 2:00 pm eastern

Yesterday, VOR members received the fourth installment of Stephanie Vance's online advocacy training course, free to VOR members. The date for her free "Chat Hour" was incorrect. The correct date is February 8, 2012 at 2:00 pm. To join "Advocacy Guru" Vance for this free chat session on effective advocacy, go to www.join.me and type "advocacyguru" (no quotes) in the join box. Then click on the bubble to chat. It's all free!

Advocacy Toolkit for Families

4. Oklahoma Families Vision for the Future of its ICFs/MR: A Safety Net for Oklahoma's Most Vulnerable

January 2012 * By the Southern Oklahoma Resource Center
Parent Guardian Association and the Oklahoma Public
Employees Association

Summary

The Northern Oklahoma Resource Center of Enid (NORCE) and the Southern Oklahoma Resource Center of Pauls Valley (SORC) have been home to thousands of Oklahoma's citizens challenged with disabilities since early in the last century. Both facilities are intermediate care facilities for persons with mental retardation (ICFMR) and receive funding from the federal government through the Medicaid program. The 245 residents who currently call NORCE and SORC home are challenged with severe physical and mental disabilities.

NORCE and SORC serve as a public safety net for the developmentally disabled service delivery system. In addition, the facilities are a critical part of the full continuum of care in developmental disabilities, from individuals in facilities requiring around the clock medical attention to those in community settings that need minimal in-home support.

The PGA/OPEA Vision for the Future of NORCE and SORC does consider the concerns and recommendations of the parents and guardians first and foremost. The employees of both facilities emphasized above all else that they support the parents and guardians in their choices for their loved ones and are gravely concerned with transitioning vulnerable clients from their lifetime homes.

[Read detailed presentation here](#)
[Related news](#)

Reaching the Media

5. What Virginia's center's closing means for disabled residents and families

Elaine Senft * *Washington Post* * January 31, 2012

The residents of the Northern Virginia Training Center, including our 39-year-old son, are absolutely not “isolated and rarely [allowed] . . . to interact with people who are not disabled,” as federal investigators concluded [“Va. to transform care of developmentally disabled,” front page, Jan. 27]. Hundreds of volunteers come to the center for special activities, to hold worship services, to play games, to read with individuals and to do countless other things that make life fun. Residents are taken to Washington Redskins games, the Kennedy Center and many other outside venues.

Within their capabilities, residents have the opportunity to express their wishes, from choosing what to wear on a given day to letting the staff know what TV show they want to watch.

It has been rare over the past several years for someone to be admitted to a Virginia training center, and admissions have usually been prompted by the relentless insistence of a parent or guardian when a major crisis arises in a disabled person's home.

It is going to be costly to set up dozens of group homes to house the de-institutionalized. At the training centers, the therapists, doctors, nurses, social workers and other specialists are within walking distance of the residents.

That won't be the case when group homes are scattered throughout Northern Virginia.

The Justice Department and the Virginia Department of Behavioral Health and Developmental Services have heard the voices of training center families and have chosen to create greater angst in families whose loved ones are about to lose their happy homes. The lives of the former residents may be put at risk, the savings that the officials project will not be realized, and taxpayers will bear the increased cost.

6. Illinois: A voice for most vulnerable

**Rita Burke, President, Illinois League of Advocates for the Developmentally Disabled; VOR State Coordinator
State-Journal Register * January 27, 2012**

Illinois' State Operated Developmental Center families and guardians are deeply concerned that your Sunday editorial supports the Quinn administration's decision to close Jacksonville Developmental Center and other centers that are the very life-lines for our loved ones. We are the voice for Illinois citizens with the most severe developmental disabilities who will be victims in this ruthless budget-cutting plan. But, for far too long, our voices have not been heard — especially not by the governor, who, to this date, has not met with us.

Your editorial calls the proposed closure an "important, much-belated milestone" in moving away from "excessive reliance" on state centers to treat those with developmental disabilities. The relocation of hundreds of fragile people deserves more than sound bites. Certainly, it deserves more than the governor's plan to displace hundreds of vulnerable people from 24/7 professional care to underfunded community agencies at currently unavailable community settings.

Our family members require 24-hour professional care due to significant medical fragility, extreme behavior disorders and profound intellectual disabilities. SODCs provide that high level of care with 24-hour, on-campus professional support as well as "career" direct care staff. "Community care" simply cannot provide that necessary care.

Many SODC families can attest to the horror of inadequate community care from which their loved ones were expelled, in some cases to psychiatric wards or to the criminal justice system. SODCs are the right treatment fit for these high-needs people.

We appreciate your paper's continuing interest and will hold you to the pledge for a dialogue including families who best know their loved ones' needs. We plan to work with policy-makers to preserve access to SODCs and ensure that residents are appropriately served and their families' wishes are embraced.

7. California - Call for oversight: Pets or people?

Tony Myers, president, California Association of Psychiatric Technicians * The San Diego Union-Tribune * Feb. 1, 2012

I was intrigued by the story on the idea to regulate and license dog groomers in California ("Bill would license pet groomers," Jan. 31). Our four-footed loved ones are deserving of safety. But what about our human loved ones?

Thousands of Californians with developmental and physical disabilities are being cared for by unregulated, unlicensed "direct-care professionals" with a few days' training in group homes with little oversight and few inspections. The arguments against regulating these "professionals" and their workplaces are the very same as those against regulating the grooming industry: It costs too much.

I'm proud to say that I'm a licensed California psychiatric technician. I spent 12 months in full-time college-level classes doing both clinical rounds and theory to learn this nursing specialty, which focuses on caring for people of all ages with developmental disabilities and mental illnesses. I pay my licensure fees, which fund our regulatory board, which oversees our ongoing educational and regulatory requirements.

"We need basic safety for our pets," said Sen. Juan Vargas in the article; an admirable goal. But don't we also

need basic safety and professional care for our most vulnerable Californians?

8. New Jersey: Gov. Christie views developmentally disabled individuals as 'pot of money'

**Salvatore Pizzuro * NewJerseyNewsroom.com *
January, 27, 2012**

About the author: Dr. Salvatore Pizzuro, a Disability Policy Specialist, holds a doctorate in Developmental Disabilities from Columbia University and an advanced degree in Disability Law from New York Law School.

Excerpts ([read complete commentary here](#))

The burning issue regarding the potential closing of developmental centers for people with developmental disabilities has quieted down but not gone away. The controversy of whether the larger institutions should be closed, and the clients returned to their parents or other family members or placed in group homes has yet to be resolved. Governor Christie has proposed closing some of these facilities, with the Vineland Developmental Center receiving the most publicity.

The Governor proposes closing facilities such as Vineland, which he compares to a “pot of money.” He proposes using the “pot of money” for creating community grants, with some of the grants going to the families of the developmentally disabled clients to be used for care in the home. Other dollars would potentially be used by the group homes.

Interestingly, New Jersey is faced with an overwhelming waiting list of clients with developmental disabilities who need housing. Most of the parents have died or are elderly and can no longer care for their adult children with special needs. Yet, the Governor suggests keeping the clients at home where family care no longer exists. It is unfortunate that the current administration views the developmental centers as no more than a “pot of money”.

The waiting list for housing among these disabled individuals continues to grow every day as new applications for housing are submitted. In addition, the

Administration has erroneously suggested that the famous “Olmstead” decision mandates closing the facilities.

Among the most pressing issues to be addressed for a special needs student who is approaching young adulthood is the problem of an appropriate living arrangement. Although mandates specify timelines and types of services, in many cases, neither the Congress nor the federal courts truly consider costs to state or local governments when passing or interpreting mandates. Nevertheless, the courts should consider a continuum of settings (moving from the most restrictive to the least restrictive) when determining the most appropriate placement for an individual with a mental disability. Within the schools, as mandated by State and federal law, children must be educated within the Least Restrictive Environment (LRE). The courts have determined that adults with disabilities who require treatment, must receive residential services in the Least Restrictive Alternative (LRA).

The *Olmstead* decision was not an integration mandate, but a Supreme Court ruling that would provide clients with an option under certain conditions. *Olmstead v. L.C and E.W* granted the right of residents of large institutions the right to transfer to the community if they if they voluntary requested the transfer and if it could be determined that they could receive appropriate services in the community. The current Administration has a simplistic view of issue of housing and treatment for people with developmental disabilities. The Governor held one of his famous town hall meetings in Vineland, New Jersey, with the parents of some of the Vineland Developmental Center residents attending. At the Town Hall meeting he repeated his plan to transfer the “pot of money” from the residential treatment facilities to other settings. Unfortunately, the variable that the Governor interprets to be a “pot of money” consists of real human beings who are fighting for an appropriate place to live with appropriate treatment and a reasonable quality of life.

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