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Speaking out for people with intellectual and developmental disabilities

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December 14, 2012

VOR Weekly News Update

News and views for VOR Advocates

"I will say it again, thank YOU VOR for all that you do for the cause, not just our specific cause, but everyone's. I think that VOR is awesome. I cannot even imagine where we would all be without your unending and fabulous help and guidance." ~ **L.K., VOR Member from Virginia**

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Quotables by, Heidi Oran, Social Networking for Social Good

Coming Up: Holiday Cheer: The joy of home, horses and "Hollywood" touching the lives of people with developmental disabilities; plus State News (Illinois, Virginia)

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VOR and YOU

1. VOR brings hope to Kentucky grandmother: Sheba and Ryan's story

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"I am overwhelmed with appreciation to what you all have done today. I have always felt my 'Ryan' only had my voice to help him. Now I know there are others who will help him when needed. If I could I would have Ryan with me every day. He is a joy to me but he does require more than me. I truly appreciate anything can be done for him."

This was written by Sheba, Ryan's 82-year old grandmother and guardian. She was expressing appreciation to a team of people in her State of Kentucky, including Tamie Hopp; VOR member Don Putnam; and Kentucky officials who, at Don's urging, acted quickly to address serious quality of care concerns involving Ryan's community placement.

Sheba found VOR after reading about our organization in an Annie's Mailbox column. Like so many families we have heard from in response to that column, Sheba worries about Ryan's future due to her age and Ryan's level of disability.

"He'll eat most anything, he needs help in virtually every aspect of self-care, and he's really fast and strong," she says. "In a second he can be out the door and into danger."

When she contacted Julie Huso, VOR's Executive Director, Ryan was living in a group home by himself in a bedroom with no heat. All other residents had been moved out. In prior months she had managed to get the place cleaned up so it was sanitary, and help stock it with fresh food."

"He's 6 feet tall but only weighs 126 pounds," she said. "He's dealt with E-coli and H-pylori infections before due to unsanitary conditions. I've dealt with that but now I worry about the very lonely, isolated situation he's in. He has no roommates and will stay in the house for days. Staffing is often inadequate which means he comes home to me and his grandfather. At least he's taken care of during those times, but it is a lot for us to manage at our age."

As things stand, staffing has improved, the home is cleaned and food is stocked and fresh. But, most importantly, Ryan will be getting a new placement near the end of December, according to Kentucky officials.

"I pray for a happy ending," said Sheba. "Thank you for everything."

2. Legal Victory in Pennsylvania

On December 12, 2012, the United States Court of Appeals for the Third Circuit released its judgment anddecision on an appeal brought by families who challenged the lower court's denial of intervention, approval of an overly-broad class definition, and approval of a settlement.

On all three arguments the families prevailed. The federal Appeals Court vacated the District Court's denial of intervention with instructions to the District Court that it grant intervention as a matter of right. In addition, the Appellate Court vacated the certification of the class ***and*** approval of the settlement indicating that while it makes no opinion on these issues, the family intervenors must be given the opportunity, as "proper intervenors," to challenge the settlement and to seek decertification of the class.

The class definition which will now be revisited by the District court includes all residents of state-operated ICFs/MR who "do not oppose" community placement, without regard to individual capacity to object to community placement. If the class remains decertified by the lower court, the lawsuit would

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VOR.net: Your one-stop advocacy resource proceed on behalf of just the five named plaintiffs (represented by Protection and Advocacy) who seek community placement and not a class of more than 1,000, many of whom require ICF/MR care.

VOR has supported intervenors in this lawusit, helping to secure *pro bono* counsel (Ben Hoffart, Sidley Austin, LLP (New York)) and participating as*Amicus Curiae* throughout the case. In support of this most recent appeal, VOR with 92 individuals filed an*Amicus Curiae* brief supporting the families request for intervention and their objections to the settlement and class certification.

Special thanks to attorneys at DLA Piper (Philadelphia), especially attorneys Lesli Esposito, Nancy Rappaport, and Jill Czeschin, who represented VOR *pro bono* as *Amicus* in support intervenors in this action. Special thanks also to Ben Hoffart and also to Carl Solano of Schnader Harrison Segal & Lewis who, on behalf of his sister, has also participated *pro bono*.

The case is B*enjamin v. Pennsylvania Department of Welfare*.

3. Hot off the press: "The National Council on Disability can't be serious," a new blog by David Kassel - Visit and Comment!

***COFAR Blog* * December 14, 2012**

A key sign that ideology has taken over rational thinking in an organization is that the organization ups the ante on a given issue by taking progressively more radical positions on it.

At a certain point, the organization’s position reaches the level of the absurd, and that is what seems to have happened in the case of the National Council on Disability’s (NCD's) latest position in favor of deinstitutionalization of the intellectually disabled.

Read More and Comment

Related: VOR Calls NCD's Toolkit "Reckless"

4. The importance of guardianship: Judge calls conservatorships a ‘celebration of family’; unique collaboration helps many

families

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***Los Angeles Times* * May 21, 2012**

In a unique collaboration of L.A.-area institutions – called the Family Matters project -- 15 families are awarded limited conservatorships (guardianships) for the protection of adult children with disabilities.

For 18 years, Dora Sanchez Hernandez has fiercely protected her son.

From the time Erik Esequizel was born prematurely at just 24 weeks, she has been there for him. Through 50 surgeries and two near-death episodes. Through the daily demands of feeding, bathing and dressing. Through abandonment by his father and advice from doctors to pull the plug.

Now — in what L.A. County Superior Court Judge Michael I. Levanas called a "celebration of family" — Hernandez and 14 other families have been granted limited conservatorships over their disabled children. It allows them to make medical, educational, business and other decisions for their children even after they turn 18.

The courtroom session last week marked a unique collaboration among the L.A. County Superior Court, the Los Angeles Unified School District, private attorneys and Bet Tzedek Legal Services, a nonprofit that assists the poor. To make what can be an intimidating process efficient and comfortable, the parties come together four times a year to act on the conservatorship cases in one courtroom over one afternoon.

The demand for such aid is enormous: The Family Matters program has served about 100

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families so far, but more than 26,750 L.A. Unified students are moderately or severely disabled.

Read more

Focus on New Jersey

5. NJ: Governor signs Tara's Law to protect the developmentally disabled in community settings

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The Record **(North New Jersey) * December 9, 2012**

Community-care residences for the developmentally disabled will get more rigorous oversight under legislation signed into law by Governor Christie on Thursday.

Tara's Law is named after Tara O'Leary, a disabled woman who died in November 2008 after suffering from dehydration and malnutrition and withering to 48 pounds while living in one of the residences in Hunterdon County.

Unlike group homes and supervised apartments operated by community agencies that specialize in caring for the developmentally disabled, the affected residences are essentially foster homes. While living in the residences, the individuals — who suffer from disabilities that range from cerebral palsy to severe intellectual defects — are supposed to be overseen by case managers from the Division of Developmental Disabilities and usually attend day programs operated by independent service providers.

But, as O'Leary's case made clear, that doesn't always happen. There are about 600 community care residences licensed by state, which are home to more than 1,200 individuals.

In February, the owner of the foster home where O'Leary lived and the state caseworker responsible for overseeing her care were sentenced to three years in prison after pleading guilty to neglect of a disabled person and theft.

"It is beyond unconscionable that a developmentally disabled person under community care could literally waste away to nothing without anyone taking any action," said Assemblywoman Valerie Vanieri Huttle, the Englewood Democrat who was a co-sponsor of the law. "If we can spare even one family the kind of pain and suffering that Tara's family went through, then this legislation will have been a success."

The law requires tighter oversight of state caseworkers as well as the residences.

Read More

6. NJ: Relatives seek reversal of plan to close Woodbridge Developmental Center

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***Courier News* (Central New Jersey) * December 9, 2012**

For Marilyn Carr, the Woodbridge Developmental Center is her 53-year-old son Eugene's home, the place where he has lived for the past 37 years.

And the people who work at the Rahway Avenue facility are his family.

"And they are my family, too, because they take care of my son, and I can't," said Carr, who moved to Rahway to be near her son after raising her family in Woodbridge and South Amboy. "The workers there are our family."

Carr said the 68-acre developmental center campus setting has all of the services to help her son, who has limited cognitive ability and was not expected to live past his second or third birthday.

Plans are in the works to close the facility and relocate many of the residents to group homes in communities throughout the state. But Carr thinks that her son will not get the services and attention he currently does under this plan, and she is concerned that her son will be moved so far away that she will never get to see him.

"I don't understand why this is happening after all these years. It's man's inhumanity to man, as far as I am concerned," she said. "There is no reason for it."

She would like Gov. Chris Christie to reconsider plans to close the developmental centers.

Carr is among a group of people with relatives living at the Woodbridge Developmental Center who are expected to attend a public hearing planned for early next year to discuss the state's plans to close the Woodbridge facility. The State Senate Health and Human Services Committee and Assembly Human Services Committee hearing will be co-chaired by state Sen. Joseph Vitale (D-Dist. 19) and Assemblywoman Valerie Vainieri Huttle (D-Dist. 37h).

Read More

7. NJ: Argument to keep Woodbridge Developmental Center open

Courier News **(Central New Jersey) * Dec 7, 2012 * Family editorial**

About the author: Leonard Lorensen, who lives in North Carolina, is the brother/guardian of Robert "Bobby" Lorensen, who was born in Summit and lived in Chatham before being placed in a developmental center.

My brother, Bobby Lorensen, is 68 years old and incurred severe brain damage at birth in 1944. He has suffered from profound mental retardation his entire life.

He has lived in a developmental center for 60 years now. Despite the fact that he is nonverbal and functions on the level of an 18-month-old, Bobby has led a contented and healthy life at Woodbridge.

Both of our parents have long since died. Bobby and I rely on the caring and professional staff at Woodbridge to be his family and see to his every day needs while maintaining his

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dignity, which they do quite successfully.

Relocating Bobby to different developmental center would be traumatic for him. In his 1991 and 1994 records at Woodbridge, it is documented that Bobby has “a fear of new places” and should not be moved. In 2003, his social worker indicated her concern about moving Bobby from one cottage to another because of his strong dislike of change. An attempt to move him into a family living arrangement proved to be very unsuccessful.

There are other important reasons why Woodbridge should not be closed. Bobby and others receive top notch care there. Doctors, nurses, social workers, therapists, personal care assistants and many other employees provide a great quality of life for the residents.

Woodbridge family members, many of whom are elderly and have no transportation, would have much difficulty traveling a long distance to a different center. Ninety-six percent of families have signed letters stating they want their loved ones to remain at Woodbridge.

I want my younger brother to stay at his home at Woodbridge Developmental Center living in good health and with a good quality of life. Bobby really is happy at Woodbridge.

We must not forget that the residents of Woodbridge are humans with feelings relying on the care of others and not case numbers used to satisfy a political agenda.

8. NJ: South Plainfield couple wants Woodbridge Developmental Center to remain open

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Courier News (Central New Jersey) * Dec 7, 2012
***Editorial by Donald and Virginia O'Brien**

Our daughter, Catherine O’Brien, is 51 years old and incurred severe brain damage at birth. She is classified as profoundly retarded and functions at a 7-month age level.

She has been a resident at Woodbridge Developmental Center since it opened in 1965 and is content and happy there. Cathy is nonambulatory and must be transported in her wheelchair wherever she goes. She must be transferred cautiously to prevent injury. She cannot talk or verbally communicate her needs. She is subject to seizures, requires a special diet developed by the staff nutritionist to prevent severe dysphagia and has many other health issues. She is totally dependent upon the professional staff for all her everyday needs on a 24/7 basis, as are the majority of the clients at the developmental center.

She receives the best of care there. The professional doctors, nurses, social workers, therapists, personal-care assistants and many other employees on staff provide a high quality of life for Cathy and all the residents.

She is classified as not being a candidate for living in a community home by the professional staff interdisciplinary team at her cottage and we strongly agree. She becomes very upset by change and needs frequent contact with us to keep her stable and happy.

We visit Cathy weekly to check on her health and well-being. Closing Woodbridge would be a hardship on us as we are in our late 70s and we are not sure how long our health will allow us to drive a long distance to see Cathy. (Woodbridge is just 11 miles from South Plainfield; Vineland is 105 miles each way.) We might only get to see her two or three times a year, or not at all, if we are not able to drive that far.

Ninety-six percent of families who responded to a Parents Group survey have signed letters stating they want their loved ones to remain at Woodbridge. The state is not allowing parents and guardians the right to choose where their loved ones would be sent if transferred to another developmental center. They also are not allowing the other centers to talk to us or visit their facilities.

These residents are our most vulnerable citizens who cannot speak for themselves and should not be dumped by the state to satisfy a political agenda. We feel their rights are being denied.

9. NJ: Parents of Intellectually Disabled May Soon Get ‘Bill of Rights’

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***New Jersey Spotlight* * December 11, 2012**

The parents and guardians of intellectually or mentally disabled children deserve a “bill of rights” addressing the information and treatment they receive from public agencies and care providers, legislators were told at a hearing on Monday.

The “Bill of Rights for Parents of Persons with Intellectual Disabilities” was approved by the Assembly Human Service Committee after providers testified about the need to improve communication with parents.

The bill includes the right to be treated with consideration and respect; receive information necessary to make informed decisions about the care of a child; receive information in writing; receive return phone calls within a reasonable time frame; get clear information about services; participate in their child’s care; have a method of recourse if they feel their child isn’t receiving adequate and appropriate care; be free from retaliation for complaints; and be advised of laws and rules that apply to their ability to access information and participate in decisions.

The bill is supported by a group fighting a state plan to close two developmental centers, which are state-operated residential facilities. However, the group -- Save Residents’ Homes at Development Centers -- did criticize the measure for lacking an enforcement mechanism or penalties for violations.

In a statement, Save Residents' Homes at Developmental Centers member Joanne St. Amand of Cranford noted that family members of developmental center residents already are protected under federal law.

Read more

Medicaid News

10. Quality of Care Oversight in Medicaid Waiver Programs - Health and Human Services Office of Inspector General (OIG) Reports

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U.S. Department of Health and Human Services (HHS), Office of Inspector General (OIG) * June 27, 2012

- Full HHS OIG Report
- Listen to Podcast / Summary of Report
- Read transcript of Podcast

Excerpts from Podcast:

"These [Home and Community-Based Services Waiver[programs primarily serve the elderly and the disabled - people who are among Medicaid's most vulnerable populations. And the very nature of the programs puts them at risk of receiving inadequate care. Most programs allow beneficiaries to be cared for by nonprofessionals without medical training.

"And, what's more, beneficiaries receiving care in their homes are often alone and isolated from observers who might detect abuse or mistreatment. This is very different from the situation in nursing homes, where there are a lot of people who can detect and report potential abuse .

"Well, we went through the data that CMS collected, and we saw that CMS was aware of a lot of significant problems. CMS's data showed that 7 of the 25 States we reviewed did not have adequate systems in place to ensure the quality of care."

11. Personal Care Services: Trends, Vulnerabilities, and Recommendations for

Improvement - Health and Human Services Office of Inspector General (OIG) Reports

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U.S. Department of Health and Human Services (HHS), Office of Inspector General (OIG) * November 15, 2012 Podcast

- Listen to the Podcast
- Read the Transcript
- Read the Portfolio (full report)
- Read the Spotlight

Excerpt from Report's Spotlight:

Medicaid provides coverage for personal care services (PCS) such bathing, light housework, or meal preparation for eligible seniors, people with disabilities and others.

OIG is committed to ensuring that adequate safeguards exist to prevent fraud, waste, and abuse in this important and growing benefit of Medicaid Personal Care Services (PCS).

Over the past 6 years, OIG issued 23 reports on the topic of PCS and conducted numerous investigations involving PCS fraud. Our latest product, an OIG Portfolio entitled Personal Care Services: Trends, Vulnerabilities, and Recommendations for Improvement, synthesizes this body of work and offers new and comprehensive recommendations to address vulnerabilities.

As described in the Portfolio, our audit and evaluation work revealed a pattern of improper PCS payments linked to lack of compliance with State policies and requirements and found that existing controls designed to prevent improper payments are ineffective. Furthermore, PCS fraud -- including many cases when the care attendants and the beneficiaries act as co-conspirators to scam the Medicaid system -- is on the rise, representing more cases investigated by State Medicaid Fraud Control Units than any other type of Medicaid fraud.

12. GOP governors seek leeway on Medicaid

expansion; Obama says no

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- States cannot do partial Medicaid expansion, says Obama administration (December 10, 2012)
- White House drops support for major Medicaid cut
- Governors seek leeway on Medicaid expansion (December 10, 2012)
- Governors seek leeway on Medicaid expansion (December 8, 2012)
- Weighing the cost against health

Governors seek leeway on Medicaid expansion * Washington Post, December 8, 2012 (Excerpts)

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Republican governors are ratcheting up pressure on President Obama to scale back a key provision of his health-care law.

In a letter to Obama last week, 11 governors asked for a meeting “as soon as possible” to negotiate for greater control over their Medicaid programs.

Among other things, the governors want the option of expanding Medicaid — the state-federal program for the poor and disabled — in a much more modest way than envisioned in the law.

The letter was signed by Jan Brewer of Arizona, Bobby Jindal of Louisiana, Rick Scott of Florida, Robert F. McDonnell of Virginia and the governors of Iowa, Maine, Mississippi, Ohio, South Dakota, Utah and Wyoming.

The law calls for opening the program to people with incomes up to 138 percent of the federal poverty level, or about $31,810 for a family of four. That’s more generous than what many states offer. It would result in about 18 million Americans being newly enrolled, according to recent estimates by the Kaiser Family Foundation and the Urban Institute.

In June, the Supreme Court ruled that the federal government cannot penalize states for refusing to go along with the full Medicaid expansion called for in the law as of 2014.

Since then, state officials have floated the idea of partly expanding Medicaid. But legal scholars sharply disagree over whether Obama administration officials have the legal power to authorize partial expansions.

Because scholars disagree on just what is mandated, some Governor's feel stuck in limbo and are hesitant to accommodate Medicaid expansion when they don't yet know who (and how many) will be newly-eligible.

Under the law, the federal government would pay the full amount of covering the newly eligible recipients for three years. The federal match would phase down to 90 percent by 2020. But that's still much higher than the regular federal match rate for Medicaid, which varies from 50 percent to 78 percent.

The governors pushing for a more modest approach want to get the enhanced federal match for a partial expansion — covering people with incomes of up to, say, only 100 percent of the poverty line.

Read more

Quotable

"It is as if a light bulb has gone on, and we're all starting to realize that those of us who are able to freely use our voices, need to use them to represent those that are not. - Heidi Oran, ConsciousPerspective.com(Social Media for Social Good in 2012)

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