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with intellectual disabilities

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VOR and You

1. Memorial planned for Robin Sims

On May 20, 2012, the Bloomfield Recreation Commission is planting a tree and dedicating a plaque to Robin Sims at Felton Field in Bloomfield, New Jersey. Felton Field is where the Challenger League plays its games. The Challenger League is for special needs athletes; Robin's son, Benny, has been a participant. The ceremony in Robin's memory will begin at 10 am, with the Mayor, several town officials, Robin's family and friends, and advocates will be present. Jack Sims and Geoff Dubrowsky, Robin's brother, asked that this announcement be shared with VOR members. Anyone who would like to join in this celebration of Robin's life are encouraged to attend.

[Read VOR's Tribute to Robin Sims, VOR's Past President.](#)

Federal News

2. HHS announces new Affordable Care Act options for community-based care

U.S. Department of Health & Human Services * April 26, 2012

HHS announces new Affordable Care Act options for community-based care Medicaid and Medicare introduce greater flexibility for beneficiaries to receive care at home or in settings of their choice.

New opportunities in Medicaid and Medicare that will allow people to more easily receive care and services in their communities rather than being admitted to a hospital or nursing home were announced today by Health and Human Services Secretary Kathleen Sebelius.

HHS finalized the Community First Choice rule, which is a new state plan option under Medicaid, and announced the participants in the Independence At Home Demonstration program. The demonstration encourages primary care practices to provide home-based care to chronically ill Medicare patients. Both are made possible by the Affordable Care Act. Studies have shown that home- and community-based care can lead to better health outcomes.

The final rule released today on the Community First Choice Option provides states choosing to participate in this option a six percentage point increase in federal Medicaid matching funds for providing community-based attendant services and supports to beneficiaries who would otherwise be in a nursing home or other institution.

For more information:

[Administration for Community Living](#), [Community First Choice Option](#), and [Independence at Home demonstration](#).

3. CMS Makes Another Run at Denying Choice

LTO Ventures, Mark L. Olson * April 27, 2012

On May 3, 2012 the Centers for Medicare & Medicaid Services (CMS) will post a [Notice of Proposed Rulemaking \(NPRM\) as CMS-2249-P2](#) that includes another significant effort to define “home- and community-based settings” in a way that EXPRESSLY DENIES CHOICE. The NPRM will invite public comment. We invite anyone with an interest in this issue and a desire to make your voice heard to read the NPRM document (pay particular attention to pages numbered 67-73, 79-89, and 147-153) and submit your comments according to the submission criteria.

VOR has submitted comments on this issue in the past, in [August 2009](#) and [April 2011](#).

State News

4. Illinois: Area's Small Group Home Operator Says Governor 'Could Be No More Wrong' In Closing Murray Center

WJBD Radio (Salem, Illinois) * April 20, 2012

Normally the President of the Penta organization says he would be on the side of closing a large developmental facility like the Murray Center. But Greg Shaver says not this time. He feels the Governor could not be more wrong.

[Read more.](#)

Related news: [U.S. Congressman against Closure of Murray Center](#), and a [terrific editorial](#).

5. Virginia: ADA settlement receives mixed reactions

Hopewell News & Patriot * April 14, 2012

See related news: [Families speak on DOJ and Commonwealth's settlement](#) (April 26, 2012)

On March 2, Pennsylvania-based York Legal Group filed a motion to intervene and motion to dismiss on behalf of a group of families of individuals who live in state run training centers. The families believe that the closure of the centers would violate their family member's rights and object to the fact that they were not consulted during negotiations between the state and Department of Justice as to the closure of the centers where their loved ones have been receiving care.

On March 6, U.S. District Judge John A. Gibney issued an order permitting interested parties to submit "briefs amicus curiae"* or "friends of the court briefs"* arguing for the submitter's perspective. In the order, Gibney said that he had heard from families concerned about the closure of the centers and others supporting the transition of the approximately 1,000 people now housed in Virginia's training centers into community based care. "These voices-on both sides-shall be heard,"* the order said. Stakeholders had until Friday, April 6, to submit their thoughts, an opportunity taken by groups in support of and in opposition to settlement.

VOR submitted a comment opposing the settlement as currently written.

"While [the settlement's] intent is to expand community based care, it imposes that option on everybody, including their family members,"* said Tamie Hopp, director of government relations and advocacy for VOR, a national legal group that supports the

legal arguments of family members of training center residents and has been offering its advocacy support regarding the current settlement.

“They believe strongly that will be the outcome should the settlement agreement be implemented as currently proposed,”* she said.

On April 6, the Washington D.C.-based Judge David L. Bazelon Center for Mental Health Law and Richmond based law firm Williams Mullen filed a statement supporting the settlement agreement between the Commonwealth and the Department of Justice.

Jennifer Mathis, Deputy Legal Director for the center, said that the current settlement with Virginia is the first Justice Department settlement focused exclusively on individuals with intellectual and developmental disabilities, which the center sees as an important development in Olmstead enforcement, and one that shows a strong commitment from the federal government.

“Frankly, if this type of settlement were derailed, I think...that would be very problematic for thousands of people with intellectual disabilities and their families in Virginia, as well as being problematic for nationwide Olmstead enforcement.”*

For VOR, Hopp said that while the families are not opposed to the expansion of community based services in Virginia, an area in which the state has been lacking, they are opposed to moving their own loved ones out of the setting they have determined provides the best care for them.

“What they’re not opposed to is [the settlements] expansion of community based settings. They would agree that Virginia needs more community offerings for people who choose that,”* she said. “There are some profound needs in Virginia...their intervention is their opposition to having reform happen on the backs of their loved ones.”

VOR is unique among national advocacy groups in objecting to the settlement, which points to their unique perspective on services.

“We are the only national advocacy group that supports a full array of services, to include the training centers, to include community, to include home care,”* Hopp said, noting the various needs of those suffering from various disabilities.

“That’s really the crux of our position. We feel strongly that one size doesn’t fit all, meaning that true person centered planning requires a range of options, a continuum of options. We would agree that the vast majority of people in the disability spectrum are better served in smaller, community based settings, but there’s a percentage of individuals whose needs are so extreme

that really, the training center option is the best option, is the least restrictive option, for those individuals because of their intense needs.”

Hopp said that VOR said it has been watching the actions of the Department of Justice in other cases similar to this one, and sees in the department’s actions, “an imposition of their ideology, a drive towards closure, a misinterpretation of Olmstead, we submit.”

Her organization decided to get involved in the current issue because they opposed the action and knew they would present a different perspective.

“We found the actions by the Department of Justice and the state so offensive really, with regards to the rights of families and their loved ones, that it’s the kind of place where VOR will offer a voice because we know it will be unique and separate from what other advocacy groups will bring to the table,”* Hopp said.

See also, [Virginia's training centers serve many well](#)

6. New Jersey: More families react: Christie's proposal to close N.J.'s developmental centers

Salvatore Pizzuro (Commentary) * April 12, 2012

In recent weeks, I have been inundated with telephone calls and email messages from the families of residents of New Jersey’s developmental center. These disillusioned people suggest that their rights have been violated by the Governor who is moving to remove their loved ones from the residential centers, against the will of the families and the residents, and transfer them to the community.

The most recent complaint was shared with me by Peter Banos, whose sister has been a resident of the Woodbridge Developmental Center for forty years. Peter is a member of the Woodbridge Developmental Center Parents Association. His message is clear: there is a need for the developmental centers, and their recommended closing has more to do with dollars than the welfare of the residents. In addition, a sufficient number of appropriate community settings simply do not exist. This writer’s position has been clear: people who choose to be transferred from the larger centers to community placements have a right to do so. However, the families have universally complained that they are part of the decision-making process.

[Read more.](#)

Research News

7. Symptoms Of Fragile X May Be Reversible

Disability Scoop * April 12, 2012

A new study indicates that medication can reverse many of the defining symptoms of fragile X syndrome in mice, a finding which could have implications for people with other developmental disabilities too.

[Read more.](#)

8. Study: Autism Can Be Diagnosed In Minutes

Disability Scoop * April 11, 2012

It often takes hours for a clinician to diagnose a child with autism, but a Harvard researcher now says it may be possible to complete an assessment that's just as accurate within minutes. Using a Web-based tool that relies on just seven questions and a short home video, Dennis Wall, a researcher at Harvard Medical School, says he can provide a near perfect assessment of whether or not a child has autism.

[Read more.](#)

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