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VOR Weekly E-Mail Update
June 25, 2010

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VOR and YOU!

1. ADDING VOR AS YOUR HOME PAGE

DID YOU KNOW...

When you first turn on your computer and access the web, a "home page" pops up. For many of us, that home page is whatever is set by default.

Did you know you can choose your home page. That is, you can tell the computer which website you want to automatically open every time you "launch the internet."

Did you know that the more a website is visited, the higher and higher it will climb on search results by Google or another search engine?

Did you know that by setting VOR's website as your home page, in this very easy way you have just helped VOR be more visible to anyone looking for MR/DD resources on the internet. That's because, with VOR as your home page, just by turning on the computer you have generated a "hit" to VOR's website.

Setting VOR's website as your home page is easy to do. Here's how (instructions relate to Internet Explorer).

First, go to <http://www.vor.net>.

Second, at the top of your screen look for the little house icon (this is part of Internet Explorer, not VOR's website).

Third, use the drop down arrow which is part of the house icon and choose "Add or Change Home Page." Follow the prompts to add VOR's website as your home page.

THANK YOU! By being at the top of search results, VOR will get many more visitors to our website. And, more visitors mean more **awareness** and potential **support** for our cause.

LEGAL NEWS

2. Tennessee Judge Rules for Families, against People First and DOJ

As families prepare for the closure of the Clover Bottom Developmental Center, on May 28 a court ruled in favor of the right individuals and legal guardians the right to choose another ICF/MR (deemed a "congregate" setting), even when professionals have determined the individuals could be provided in a more integrated setting.

The question before the federal district court in Tennessee was whether the Americans with Disabilities Act (ADA) precluded Clover Bottom residents, or their legal guardians, from choosing "congregate care."

The U.S. Department of Justice and People First of Tennessee argued against the right of choice when professionals have deemed another setting to be more "integrated."

Citing Olmstead and Medicaid law, the Court ruled in favor of the state and families, recognizing the freedom to choose a large ICFs/MR placement even if the individual could be appropriately served in a more integrated setting.

"The intersection of citizen choice and the ADA was addressed by the Supreme Court in Olmstead v. L.C.," wrote the court. "[T]here is no federal requirement under the ADA that community-based treatment must be imposed on citizens who do not desire it."

The Court was particularly persuaded by the brief of the Parent Guardian Association (PGA), which argued that "Conservators [and guardians] - who have the longest and most meaningful relationship with their loved ones and the greatest investment in their well-being - are in the best position" to weigh all benefits and risks of any placement option, and will give due consideration to the opinion of professionals.

There is "no merit to the contention of the United States [DOJ] and People First that the professional judgments . . . as to appropriate community placement of a class member must always prevail over the citizen's own choice (expressed individually or through a guardian or conservator) of a qualified provider."

In addition, Medicaid law also requires that recipients have the "right to choose whether to receive services through an ICF/MR or a Home and Community-Based Services Waiver," the court held.

The case is People First of Tennessee v. Clover Bottom. The decision can be found at VOR's website at <http://www.vor.net/get-help/legal-resources/>.

3. California: Procedural win is moral victory for family

On June 22, 2010, a California appellate court found that Gail Bowen's legal battles on behalf of her profoundly disabled son, Michael, should never have been. The Court overturned a lower court ruling on a January 2009 lawsuit filed the public defender to force Michael into a "community setting." The court found the filing improper because just one month earlier (December 2008), an Administrative Law Judge (ALJ) had held that Sonoma was the least restrictive environment. The lawsuit filed by the public defender amounted to a re-litigation of issues that had already been resolved.

Gail Bowen, along with Michael's father and co-conservator (James), will be the first to agree that their legal struggles, which began following a 2007 Interdisciplinary Team (IDT) meeting for Michael, were unnecessary and unjustified.

Because Agnews, which had been Michael's home since 1986, was closing, Gail sought a transfer to Sonoma. All members of Michael's IDT agreed except one: The San Andreas Regional Center (SARC), a state contracted agency charged with developing individual program plans for California citizens with developmental disabilities who are in need of services. SARC's refusal blocked Michael's admission to Sonoma, forcing his family to request a Fair Hearing before an administrative judge to appeal SARC's decision.

In December 2008, Administrative Law Judge (ALJ) Karen Brandt found in favor of the family's request that Michael be transferred to Sonoma, noting that "it was evident Michael's family was motivated by their love and devotion to him . . . [and] given his very severe and significant developmental disabilities and medical issues, a developmental center is the least restrictive and best environment for him. The determination of what is the least restrictive environment must be based upon factors that are specific to Michael's individual needs."

The public defender challenged this decision in court in January 2009 - a filing the appellate court described as "ostensibly on behalf of Michael but effectively on behalf of SARC." Still, the trial court sided with the public defender and against the family's wishes, holding that Sonoma was not the least restrictive environment for Michael.

Gail Bowen appealed and won. Although the appellate court's decision hinges on a technicality that restores the ALJ's decision in support of Michael's placement at Sonoma, it is not a hollow victory. In its decision, the appellate court also provides important guidance for other families seeking to protect developmental center placements. The due process requirements for an initial admission to any developmental center (called Hop hearings in California) are not meant to be replayed over and over again to justify continued admission or transfers to another developmental center.

"The due process concerns for retention in a developmental center are not the same due process concerns that are present when a developmentally disabled person is first involuntarily committed."

The full decision can be found at:

<http://www.leagle.com/unsecure/page.htm?shortname=incaco20100622085>

4. U.S. Supreme Court to review right of P&A to access records

As early as this fall, the U.S. Supreme Court says it will decide whether Virginia's Protection & Advocacy (VOPA) can force state officials to provide records relating to deaths and injuries at state mental health facilities. The justices have agreed to review a federal appeals court ruling dismissing VOPA's lawsuit which asserts its right to access these records.

The issue for the court is whether the Eleventh Amendment prohibits a state agency from going to federal court to sue officials of the same state. The state itself could not be sued in the same circumstances.

The case is VOPA v. Reinhard, 09-529. (Source: AP, June 21, 2010)

STATE ADVOCACY NEWS

5. New Jersey: Robin Sims' Testimony for Joint Committee

Summary: In May, Robin Sims' VOR's president, gave impassioned testimony before key New Jersey legislative committees. Her testimony is in opposition to legislative initiatives aimed at eliminating quality residential options for New Jersey families. Her testimony aimed to give voice to "families and those who are advocates for those who live in our developmental centers," who, for too long, have been without a voice.

May 7, 2010
By Robin Sims

I would like to thank Senator Loretta Weinberg and Assemblywoman Valerie Huttle and their respective committees for having these hearings today. For the first time our voice will be heard.

"For the great enemy of the truth is often not the lie-deliberate, contrived and dishonest- but the myth, persistent, persuasive and unrealistic. Too often we hold fast to all the clichés of our forebears. We subject all facts to a prefabricated set of interpretations. We enjoy the comfort of the opinion without the discomfort of thought" John F. Kennedy

For a very long time families and those who are advocates for those who live in our developmental centers have been trying to get someone to listen - someone to understand that the Olmstead Plan for the State of NJ is based on the lie/myth that claims that thousands of residents of our centers wanted to leave.

Nothing could be further than the truth.

The Division of Developmental Disabilities knows it, those who are here to selfishly promote their own agencies or those they lobby for know it, and now you will know it. We have done the best we can through our various Family and Friends and Associations of Parents from all our Centers to ask the question of all primary decision makers regarding their choice. Where do they feel their loved one can get the best care according to their needs? They spoke and have stated in overwhelming numbers that they want their loved one to remain in their current home in the Developmental Center.

Assemblyman Greenwald who had never even been in a Developmental Center was persuaded by Kim Todd (who by the way claims that she proposed the bill to Assemblyman Greenwald) decided to press the idea of closing 5 of our 7 developmental centers.

The big question for me is why?

You must know that Kim Todd is a lobbyist and the Executive Director of the NJ Association of Community Providers. Lowell Ayre is also a lobbyist for providers through his group ABCD. While he claims that the organizations he represents can serve the populations in the Developmental Centers yet none of those agencies are private ICF/MR's. But how do they pay their bills? Their members who are all community providers are assessed dues based on their contracts with DDD. This means that they are paying for their lobbying with precious state dollars. We are cutting services to families to pay for lobbying. We are using state dollars to allow an organization with much to gain by having centers closed write bills.

I have had enough. The ICF/MR program started in NJ in the late 1970's. The federal grant created standards for care and thought CMS the Centers for Medicare and Medicaid they continue to monitor all centers. I have brought a copy of those regulations with me today. As you can see they are quite extensive. According to the federal funding source for ICF/MR's or developmental centers a person must be in need of "Active Treatment." In order for a person to leave a center they must no longer need this level of care. Families with loved ones at home who need Active Treatment Plans with 24/7 care and instruction are not even allowed to visit our centers or even told about them. There is no way for a parent to go and look at this option the way they look at schools when their children are school age.

They are told things like "you don't want that, the centers are terrible". This environment of fear has kept people at home longer than many families can bear. We need to allow those on the waiting list to see the centers, receive the information about services and supports in centers in an unbiased way and let families think and decide for themselves.

I serve on the DD Council and somehow they believe that their mission is to advocate for closure but again nothing could be further from the truth. The DD Act is the federal law that established and helps to fund the DD Councils, the Boggs Center (the center of excellence) and NJ Protection and Advocacy now called Disability Rights NJ. How interesting it is that Elizabeth Boggs herself had her son live at the Hunterdon Developmental Center and now the center named for her wants to close them. What must she be thinking?

When the DD Act was drafted Congress made sure that it was clear that programs under the Act understood that "individuals with developmental disabilities and their families are the primary decision makers regarding the services and supports such individuals and their families receive, including regarding choosing where the individuals live from available options, and play decision making roles in policies and programs that affect the lives of such individuals and their families" DD Act, 42. U.S.C. 15001 © (3) (2000) (Findings, Purposes and Policies).

Congressional intent further confirms support for the provision of facility based care based on individual choice and need. It says "the committee would caution that goals expressed in this Act to promote the greatest possible integration and independence for some individuals with developmental disabilities not be read as a Federal policy supporting the closure of residential institutions. It would be to the contrary to Federal intent to use the language or resources of this Act to support such actions, whether in the judicial or legislative system" (House Energy and Commerce Report No. 103-378, November 18 1993 pages 7-8 to accompany H.R. 3505, DD Assistance and Bill of Rights Act.

And yet the DD Council in its policy statements promotes the closure of developmental centers. NJ Protection and Advocacy will not help a family of a child with the need for Active Treatment and ICF/MR services to gain access to our centers and has filed several law suits over this very issue. A state agency getting funded to sue the state - quite a concept. A Council that promotes policies that are not part of their mandate but they claim they are. Under the DD Act the words "work to close developmental centers does not appear. Period.

Family and friends of those in the developmental centers have fought this fight over and over again. The myth or lie started in 2001. A memo was sent to all the centers stating that everyone in a center was eligible to leave unless they were either 1. dangerous to others by virtue of having a criminal record or 2. they said in their own words that they wanted to stay. According to the memo that we love to call the "smoking gun memo state this was to be done no matter what the team or family wanted. It didn't matter if the person could not talk when it came to moving but it sure did count when it came to staying. According to the Developmental Disabilities Planning Institute at NJIT they determined that even when a person stated they wanted to leave the center only a small number of those who said so had the cognitive understanding of what community meant. Many stated they wanted to move but not to a group home. Some had been in group homes and did not want to return.

So what are we left with? An organization or two of lobbyists trying to get work for their members, parents not being given the opportunity to explore their choices of centers, parents and family members of developmental center residents who live in a state of anxiety and uncertainty. These folks whose children live in the developmental centers have their phone calls and visits counted and their attendance at IHP meetings noted. This is not what parents of individuals in community group homes or supervised apartments or even at home has to do. They are considered smart enough to make those decisions for their loved ones. And yet we are sent letters that state if we are opposed to community placement it must be due to the fact that we need training. News Flash: Our families are teachers, doctors, therapists, lawyers etc. We have made our choice knowing full well what options are available and have chosen an ICF/MR because it is the place where our loved ones can have the most complete life.

The lobbyists and some community parents are trying to make our loved ones the scape goats of their lack of movement from the waiting list. Our federal reimbursement rate from ICF/MR's are greater than those in the Community Care Waiver so our loved ones will cost more state dollars when moved into the community when they get the same or better services and the waiting list will grow and no emergency placements in centers will be available. People will die with inappropriate care and this has been proven time and time again. The mortality study done by DDPI at NJIT after the closure of North Princeton Developmental Center states that "The findings are limited by the amount of time that was used to assess deaths." If the time period were extended beyond 27 months, more persons would have died and the final model might have been different. Yet DDD refuses to do the follow up study. What are they afraid of? Did they lose the former residents of North Princeton DC? Can this joint committee compel them to do it?

Dr. Ted Kastner has volunteered to complete this work of a ten year look to see where those same people are today at no charge to the state. Let's let him do it. We need to know what happens to

residents who are displaced from their homes. Even with those who are leaving today it is important to track how many homes and other placements they go to once they leave the Center, how many die and how many return to the centers in damaged condition. We must declare a moratorium on all movement until these questions are answered. This is particularly important for those who are leaving without family directly involved. The Bureau of Guardianship services has not revealed to us as we did the survey on choice the number of persons on each case workers case load that was recommended for staying or moving. We fear that the numbers will be high to recommend moving as the 2001 memo ordered BGS guardians to say that they were not opposed to a community placement. How much does BGS cost us? Some states, many states in fact do not use state workers as paid guardians due to conflict of interest. They find retirees, volunteers, other parents in the DC's to volunteer to accept guardianship. The case loads for these folks are too high now to be effective advocates for all their clients.

Speaking of spending, why can't anyone at DDD or the office of the Treasury tell us how much money is being spent on Maximus? Maximus is the contracted company that does all the billing for the contribution of care for residents of DC's and group homes among other things. We in the state of NJ entered into a contract with Maximus at the same time that NYC was ending a contract with them citing fraud. We have no other bidders for this contract and so Maximus will be there screwing up the billing and billing the State of NJ millions to do what we used to do ourselves within the Department of Human Services. Everyone that we have heard of regarding Maximus states that the billing is always wrong and it takes so long for the money to go to the State Treasury, then get reported to the provider and then sent to Maximus for a now monthly billing, it is impossible to get it straight. Perhaps if this job returned to the state it would create jobs and in the end save money. Maybe the contribution of care would not have to be increased after all.

Commissioner Velez has been speaking about a survey done by the Developmental Disabilities Planning Institute at NIT. This survey was supposed to be done last summer and DDD is paying an annual contract to DDPI for hundreds of thousands of dollars each year for similar work. DDPI sent letters to families stating that they wanted to "obtain from family members of developmental center residents their understanding of community placement and their feelings regarding placement of their loved one." They wanted to know how much we knew about the community so they could what? Reprogram us? The original survey did not even have a question asking "where do you want your loved on to live?" That question was added after I insisted that it be added. The powers that be were not happy about that and put the question at question #20. It reads, "At this time, does Jane Doe prefer to live . . . 1. in a group home or supervised apt, 2. at home with you, 3. with another family member .gee when are they going to ask about the place where they are now...4. in some other setting, 5. does he/she prefer to continue living in a Developmental Center, 6. Does he/she not have any preferences or 7. Is he/she unable to express his/her preference?"

That is all folks. Bad enough our Individual Plans for our family members are written as if they wrote them in the first person. People living in waiver homes have their plans written in the third person as it should be especially when the person is not capable of doing the plan themselves. Oh yes we were asked our opinion at question 21. Same order of choice. Knowing how the majority of family members felt about moving their loved ones they proceeded to ask questions like:

Do you think that any of the following might make you think differently about community placement? The survey goes on to ask other questions regarding our knowledge of the community and what services we would need in place for us to feel comfortable for our loved on to live in the community etc. when does it end? When can we go to sleep at night knowing that our loved ones are safe and that their homes are not going to be snatched from them the minute we stop the fight or the minute we die. How do we protect those who at this moment are being targeted to move even though they do not want to go, Let us get on with the business of loving our family members who depend on us to keep them safe?

I conclude by thanking this group here for being the first group to listen to us the primary stakeholders in this discussion. I can make myself available to you at any time to discuss and all of these matters in greater detail. I want to thank my son Benny for coming here with me today. Benny is a young man with Fragile X syndrome who lives with his father and I. He wants to help his sister Heather who lives at Hunterdon Developmental Center so he came here today.

Thank you again.

Tamie Hopp, Director of Government Relations & Advocacy

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