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1. Hot off the press: Families defend rights to regulated, professional care

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***Outreach Magazine* * March 8, 2012**
* Article
* *Outreach Magazine* (see p. 6, featuring quotes from VOR leaders and photos of Aaron Underwood and Jason Anthony).

Family members of people living in developmental centers are calling on decisionmakers across the country to stop the drive toward closures impacting their loved ones. Joined by concerned healthcare professionals and caretakers, parents and siblings of Americans with developmental disabilities want to retain their choice for their loved ones to receive care in federally and state-regulated developmental centers.

FEDERAL WEB OF IRONIES

In recent years, the national demand for developmental centers' closure has come perhaps most strongly – and, perhaps, most surprisingly – from the federal government: the very federal government which requires developmental centers to meet its own regulatory standards.

To be federally certified through the U.S. Centers for Medicare and Medicaid Services, state developmental centers must meet eight major criteria on:

- Management
- Client protections
- Facility staffing
- Active treatment
- Client behavior and facility practices
- Health-care services
- Physical environment
- Dietetic services.

To meet all of these major criteria, developmental centers must comply with 378 specific federal standards and elements. Failure to comply with any one of these hundreds of requirements or to swiftly correct any deficiencies means the loss of federal certification as well as federal Medicaid funding.

But in an interesting twist, other federal funds go to support the efforts of the Protection and Advocacy system. Created by Congress, this federally mandated system acts as a legally based advocacy provider for people with developmental disabilities and other mental and physical disabilities throughout the nation. Each state has a P&A branch to investigate allegations of discrimination, abuse or other concerns affecting Americans with disabilities, wherever they reside.

The P&A system and a law called the Civil Rights of Institutionalized Persons Act originally arose as responses to widespread concerns of neglect and abuse at an unlicensed New York developmental center called Willowbrook State School more than 40 years ago. The system and the law are the bases for the regulations that today’s developmental centers must follow to achieve and continue federal accreditation. However, nothing in this system or law require the closure of developmental centers. In the case of the federal law which creates P&As – the Developmental Disabilities Assistance and Bill of Rights Act (often called the “DD Act”) – P&As board charge is to “protect and advocate” for people with disabilities regardless of where they reside. In the DD Act’s legislative history, Congress expressly cautioned against interpreting the act as mandating closures: *“The goals expressed in this act to promote the greatest possible integration and independence for some* *individuals with developmental disabilities may not be read as a federal policy supporting the closure of residential institutions... ."* This Congressional intent is reinforced in the act itself, where individuals and their families, and no one else, are named as the "primary decisionmakers" regarding services (including residential supports) and policies.

What's more, in the past few years, sometimes working in tandem with the P&A system, the U.S. Department of Justice has made developmental centers a focus, issuing investigative reports, filing suit, or presenting briefs in cases alleging violations of the Americans with Disabilities Act, seeking or supporting settlements that would cut developmental centers' populations or even close all centers in several states.

The kicker here? The DOJ – like the P&A system – targets developmental centers that have achieved licensing and certification from the federal Centers for Medicare and Medicaid Services. The DOJ does not oversee or have jurisdiction over less-regulated private developmental facilities or group homes: the facilities it is often seeking to move developmental-center residents into, whether they wish it or not, as the result of its legal efforts.

To add to the paradox, another federal group – none other than the U.S. Supreme Court – made key points in its touchstone 1999 Olmstead ruling:

"We emphasize that nothing in the [Americans with Disabilities Act] or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it."

The overall tragic irony of this Kafkaesque situation is not lost on those advocating for loved ones to have the choice of living in federally regulated and certified facilities Adding to the personal and emotional toll of advocating to keep their loved ones' developmental-center homes open, family members must use their own personal funds to fight the deep pockets of federally funded P&A and DOJ attorneys seeking center closures that families and residents often do not wish.

“The use of federal funds to dismantle an infrastructure of services for our most vulnerable citizens – those with complex medical needs like Aaron – or individuals with aggressive or self-injurious behaviors, is unconscionable,” said Rebecca Underwood, whose son lives at the Central Wisconsin Center.

“Federal funds are being used by one agency to sue another federal agency for the purpose of evicting our nation’s most vulnerable people from their homes,” added Tamie Hopp, director of government relations and advocacy for VOR, a national organization that advocates for quality care and residential choice for people with developmental disabilities. “In addition to wasting taxpayer dollars, it defies common sense and human decency.”

WHAT DOES ‘MOST INTEGRATED’ MEAN?

Those taking aim at developmental centers, in the federal government or elsewhere, feel that the centers are not the most integrated settings possible for those with developmental disabilities.

In yet another ironic twist, DOJ – the very agency charged with enforcing the Americans with Disabilities Act’s “most integrated setting” mandate, as interpreted by the U.S. Supreme Court’s Olmstead ruling, has taken to interpreting the “most integrated setting” very narrowly and inconsistently with the Supreme Court’s decision. In its “technical assistance” document on the enforcement of the integration mandate,” DOJ indicates that “[i]ntegrated settings are located in mainstream society.” But the ADA defines “most integrated setting” to be “a setting that enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible [emphasis added].”

Families with loved ones in developmental centers who wish to continue their services strongly disagree with any interpretation that their family members are, in any way, restricted. They feel that the many on-site services offered at a developmental center provide the most integrated environments possible, allowing their loved ones live securely and to meet their fullest potentials.

“The very specialized care and services my brother receives at the Bellefontaine Habilitation Center has allowed him to attain and maintain his highest God-given abilities," said Mary Vitale, whose brother lives in a Missouri developmental center. "The only reason he is alive today is this specialized care."

Jane Anthony's son Jason lives at Northern Virginia Training Center in Virginia: a developmental center slated for closure. In addition to federally regulated care for Jason – who has the cognitive functioning of a 6-month-old child, can't speak, and has limited physical mobility as well as pica, a potentially dangerous condition causing him to crave non-food items – the center includes 85 acres of maintained grounds and outdoor venues for him and others to roam and enjoy in safety.

"Saying that Jason will have more choices if he lives in the so-called 'community' is like asking Jason which car he wants to hit him," said Anthony. "It is here he enjoys real independence."

Developmental-center staff also echo families' concerns about how many group homes and placements with less safety and oversight and fewer programs can be less "restrictive."

"Developmental centers are required by federal and state regulations to have dozens and dozens of state-of-the-art therapeutic and rehabilitative programs in place, right there on grounds as well as in the broader community; but somehow a developmental center is always painted as 'less integrated' and 'more restrictive' than a house on a busy street with a postage-stamp yard, occasional visits by licensed staff, few or no programs and infrequent and pre-announced visits by state regulators," said Brad Whitehead, who has worked as a Psychiatric Technician at Lanterman Developmental Center here in California for more than 30 years and which, like Northern Virginia Training Center, is slated for closure.

"I'm not 'anti-"community"' – I've actually visited many group homes and actively advocated for group-home placements when I feel it's in the clients' best interests and is what they and their families wish; but in general, how is having more space, more programs and a whole community of people there to help you enjoy the healthiest and most active life possible ‘more restrictive?’”

FEDERAL BILL COULD MAKE A DIFFERENCE

While developmental centers continue to be caught in a perfect storm of cheaper-is-always-better fiscal conservatism and dangerous one-size-fits-all ideology, some members of the federal government are in fact taking a stand to support clients and families’ rights to choose federally regulated developmental centers: Nearly 70 Congressional cosponsors from both parties have signed on to support House Resolution 2032.

This bill represents the third try to get common-sense rights for developmental-center residents and their families and conservators. House Resolution 2032 would require legal guardians to be notified in advance of a class-action federal lawsuit aimed at closing or downsizing their developmental center, and given an opportunity to opt out if they do not wish to be a part of such a suit aimed at closing or downsizing their or their loved one’s home. The bill also would include a section that would require the U.S. Department of Justice to consult with families when investigating developmental centers because, remarkably, families are not routinely consulted in these investigations.

If DOJ opts to file a lawsuit, the bill also provides legal guardians a right of intervention in any court proceeding. “Both H.R. 2032, which will require families and guardians to be at the table before facility closure decisions are made, and reform of the Developmental Disabilities Act are urgently needed to protect the rights of our most vulnerable citizens,” said Underwood.

CONTACT YOUR CONGRESSPERSON

CAPT believes the residential choices of people with developmental disabilities should be up to them, or their families and conservators, not federal attorneys. We encourage you to contact your member of Congress and urge his or her support of House Resolution 2032. For contact information, visit www.congress.org; for more information on the national issue of developmental-center closures, visit www.vor.net.

2. EDITORIAL from Texas: Poor results on DOJ settlement scorecard do not mean level of care is substandard

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Lukfin Daily News * February 26, 2012

There is no higher calling than to take care of those who are unable to take care of themselves. People with severe intellectual and developmental disabilities certainly fall into that category, which is why we support the employees and volunteers of the Lufkin State Supported Living Center who are truly concerned with the wellbeing of its residents.

In our view, based on our own history with the facility (Editor Andy Adams has been a member of the living center's Volunteer Service Council for a while, and our reporters have also done countless stories about the Lufkin campus during its 50 years of existence), the employees and volunteers really do try to treat residents as they would want their own family members to be treated. What's more, actual family members of residents have told us — even in the last week or two — that they believe their loved ones are receiving around-the-clock quality care at the center.

All of those feelings are at odds, however, with the results of ongoing six-month monitoring reports that are required under a settlement agreement between the Texas Department of Aging and Disability Services, which operates Texas' living centers, and the U.S. Department of Justice. In its last report, a 332-page document delivered earlier this month, the Lufkin center was found to be compliant in only 26 of 171 provision areas. The Department of Justice expects the Lufkin campus to be substantially compliant in all areas by 2013.

"The third-round Lufkin review indicates major gaps in the facility's ability to meet the health and safety needs of residents," said Beth Mitchell, supervising attorney for Disability Rights Texas. "The Lufkin facility's lack of progress is distressing given how little time they have left to gain compliance. It is unimaginable that the Lufkin center will make the required improvements to the protections, supports and services it provides to residents by the mandated DOJ deadline.”

Unimaginable is one way to put it. Unreasonable is another. There are so many variables that go into taking care of people — especially those with the kinds of disabilities that living center residents possess — that it’s virtually impossible to perform perfect medical, psychiatric and social care for every single resident every single day, even over just a few weeks or months.

We take that back. It’s completely impossible. The settlement, and the lawsuit that led to it, have actually been good for the DADS system in that it has forced the Texas government to create, and pay for, a necessary increase in staff at its living centers. That means more people are providing care to residents on an hourly basis, and we honestly believe that almost all of those employees are constantly looking out for the residents’ best interests. But even with the bigger staff, and a visible, concerted effort to meet the guidelines of the settlement agreement, the Lufkin Living Center has had a hard time making the grade. That tells us — again, based on what we know about the center and its employees — that the demands simply are not reachable. (Actually, we find it amazing that the employees get anything done, with the amount of paperwork the settlement agreement requires.) That leads us to this fear: Next year, assuming the Lufkin center and its counterparts across the state are unable to complete a suitable scorecard in the DOJ’s eyes, the case will go back to court, and the groups that have been pushing for the closure of a number of these types of facilities might just get their wish. If that were to happen here, the loss of 1,000 good Texas Forest Country jobs would be awful in and of itself. The loss of the level of care that the center provides its residents would be worse. Angelina County and its Texas Forest Country neighbors have had to stand up for the Lufkin State Supported Living Center once before, but the time is likely coming when we’ll have to do it again. Now is a good time for all of Deep East Texas to make sure our representatives in our state and national governments realize how important the living center is to its residents, their families and our community.

Email: info@vor.net

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VOR
836 S. Arlington Heights Rd.
#351
Elk Grove Village, Illinois 60007
US