



Speaking out for people with intellectual and developmental disabilities



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## Reminders: Help VOR Grow!

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## VOR Weekly News Update

*News and views for VOR advocates*

**Did you receive this as forwarded e-mail? If so, someone thought you would benefit from VOR's information. Please consider [joining VOR](#) and receive this E-News Update publication weekly!**

**VOR is a national organization that advocates for high quality care and human rights for people with intellectual and developmental disabilities**

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## 1. National Council on Disability releases “Deinstitutionalization Toolkit,” says “VOR seems to have influence on policymakers that far outpaces its size

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The National Council on Disability (NCD) is a “small, independent federal agency charged with advising the President, Congress, and other federal agencies regarding policies, programs, practices, and procedures that affect people with disabilities. NCD is comprised of a team of fifteen Presidential appointees, an Executive Director appointed by the Chairman, and twelve, full-time professional staff.”

Earlier this week, NCD released a massive “[Toolkit](#)” and [companion document](#) to “provide all those interested in institutional closures and expanded community living opportunities for people with intellectual disabilities and developmental disabilities (ID/DD) with information, strategies, state data, and case studies that can facilitate closure and build community capacity to serve more people with ID/DD in the community.”

If you would like to comment on NCD’s publication, comments can be submitted to [PublicComment@ncd.gov](mailto:PublicComment@ncd.gov) or [ncd@ncd.gov](mailto:ncd@ncd.gov). VOR’s Government Affairs Committee will be preparing comments.

NCD did have this to say about VOR in the Toolkit (see, [Strategy in Detail](#), page 5):

“On a national level, the Voice of the Retarded (VOR) represents parents and family members opposed to institutional closure, and is the only national organization lobbying for the preservation of large state institutions. The exact size and membership of VOR is unknown. If compared in size with organizations that promote deinstitutionalization, such as The Arc with 100,000 members and 1,000 local chapters, VOR seems to have influence on policymaking that far outpaces its size.

“For example, in opposing the closure of institutions in Virginia. VOR argues that facilities have

better oversight, services are provided as 'wrap-around', medical staff are on site, and facilities are stable (permanent) and contribute significantly to the local economy. These assertions . . . can be persuasive if not challenged effectively."

### **State News**

## **2. New Jersey. Legislature passes Tara's Law, improving oversight of foster homes for disabled adults**

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**[NJ.Com](#) \* October 18, 2012**

A bill that would strengthen oversight of New Jersey's 600 adult foster homes and the 1,200 people with developmental disabilities who live in them won final passage in the Legislature today.

The Assembly passed Tara's Law (S599) by a 78-0 vote, and now heads to the governor's desk for consideration.

The bill is named for 28-year-old Tara O'Leary, who died in 2008 from starvation and neglect while she was under the care of a licensed foster home or "community care residence" in Bloomsbury. A state case management also was supposed to making monthly visits to O'Leary, who died weighing 43 pounds.

Among the many new requirements, the bill would require foster home providers to undergo evaluations to see if they are fit to continue caring for a disabled person, and require case managers' supervisors to visit the foster home residents every two years.

"The tragedy of Tara's death is that it was preventable," said Patrick Diegnan (D-Middlesex), one of the sponsors of the bill. "When it comes to the developmentally disabled, clear chains of communication are a literal lifeline to survival.

Systemic breakdowns in that chain simply cannot be allowed to occur again."

## **3. New Mexico Treated Like Product, Not People**

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***Albuquerque Journal* \* October 21, 2012**

A Clovis-based nonprofit organization dedicated to “enhancing the lives of people with disabilities” amassed more than \$13 million in assets in recent years, records show.

Its past president and CEO received nearly \$1 million in compensation in 2010 alone.

But five of the agency’s longtime clients contend the profits – mostly derived from government funding – came at their expense.

They allege in a state District Court lawsuit that they have been neglected, exploited and left to fend for their medical and other needs since being “dumped” into the care in the late 1970s and early 1980 of ENMRSH Inc., otherwise known as Eastern New Mexico Rehabilitative Services for the Handicapped.

That’s when the now-closed Los Lunas Hospital and Training School south of Albuquerque discharged an estimated 1,000 developmentally disabled teenagers and young adults into homes around the state without sufficient safeguards or continuing oversight, according to the lawsuit filed Oct. 4 in Santa Fe.

The lawsuit states that one of the five plaintiffs had so many unaddressed physical and emotional issues that she was hospitalized numerous times and weighed nearly 500 pounds when a caseworker from the state’s Adult Protective Services division became involved in 2003.

[Read more](#)

[Read VOR’s Letter to the Editor](#)

**4. Oklahoma: National Organization Says “Lives are at Stake”; Calls for a delay on vote on future of the Northern and Southern Resource Centers for fragile Oklahomans with profound intellectual and developmental disabilities**

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**[VOR](#) \* For Immediate Release \* October 24, 2012**

The newly-hired Director of the Oklahoma Department of Human Services, Ed Lake, has said he wants to “hit the ground running” when he takes

office on November 1.

One national organization is hoping he will trade his running shoes for walking shoes, at least to decisions pertaining to the futures of Southern Oklahoma Resource Center (SORC) in Pauls Valley, and the Northern Oklahoma Resource Center (NORCE) in Enid, which now serve 126 and 115 residents, respectively, with severe intellectual disabilities.

VOR, a national organization advocating for high quality care and human rights for all people with intellectual and developmental disabilities, has raised questions about the ability of the new Director and the Oklahoma Commission for Human Services to make an informed decision when it meets on November 1.

“November 1 marks the first day of Director Lake’s new job and only the second or third meeting for the four newly appointed Commissioners. Even the five veteran Commissioners have spent the vast majority of its time on the Children’s Rights lawsuit,” said Tamie Hopp, VOR’s Director of Government Relations & Advocacy. “For the past 11 months, the SORC family association has been allowed less than 30 minutes in public sessions of the Commission’s meetings to discuss its concerns. 10 of these minutes were only offered after a vote was tabled due to alleged Open Meetings Act violations.”

The stakes are high for the fragile individuals directly impacted by the Commissions’ decision. Both resource centers Medicaid licensed facilities serving Oklahoma’s most fragile citizens with intellectual and developmental disabilities. The vast majority of the residents at each facility have profound intellectual disabilities – the minds of infants or young toddlers – along with other disabilities, medical needs and behavioral challenges.

[Read more](#)

## **5. Connecticut: Private DDS providers left to investigate 41% of abuse cases**

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*Southbury Training School Home & School Association*

**Blog (by David Kassel) \* October 23, 2012**

More than 41 percent of the complaints lodged over the past decade of abuse and neglect of intellectually disabled people in Connecticut were investigated by state-funded, nonprofit provider organizations and not by state agencies, according to data provided by the Department of Developmental Services.

The data, provided under a Freedom of Information Act request, show that nonprofit providers, which primarily operate community-based group homes, were the sole investigative agencies in 2,750 out of a total of 6,654 abuse and neglect cases in the state between 2002 and 2012.

The OPA [Office of Protection and Advocacy for Persons with Disabilities] appears to primarily monitor investigations by other agencies. According to the DDS data, OPA monitored a total of 2,048 investigations, or 30.8 percent of the total number.

The situation is of concern to guardians of residents at the Southbury Training School (STS), who are under increasing pressure from the Malloy administration to move their family members into community-based group homes.

[Read more and comment](#)

**Inclusive ICFs/MR**

**6. California: A-A-A-R-R-R-GH is happy time at SDC**

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***Index-Tribune (Jessie Gordon, Editor) \* Oct 8, 2012***

I was lucky enough to be invited to see the Sonoma Developmental Centers production of a pirate musical called A-A-A-R-R-R-GH. When one walks in, one sees a framed photo and biography of each cast member. The printed program was the same Playbill format one would see at an ACT performance in San Francisco.

Many of the cast were in wheelchairs, but that seemed irrelevant as the play progressed. The words were projected on a big screen so the audience could participate. The songs were pirated from other sources with familiar tunes and many cries of a-a-a-r-

gh!

The clever scene changes, the inventive props, the general Jolly Roger atmosphere was impressive. Does the community hear of such a happy occasion at the center? It was a testament to the dedication and affection the staff feels toward the clients. Lets hear more of such positive news.

## **7. Texas: Richmond Supported Living Center Athlete Enjoys San Juan Special Olympics**

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***Richmond State Supported Living Center \* October 2012***

If you're feeling your age, seeing it in the mirror and about ready to surrender to the Elastic Waistband Stage of life, put down that Cinnabon and take a moment to read the story of David Anderson.

At the age of 48, Anderson — a 29-year resident of the Richmond State Supported Living Center — just won silver and bronze medals in last month's Special Olympics International Games in San Juan, Puerto Rico.

Anderson also competes regularly and at a high level in other Special Olympics events such as track and field, Level 2 springboard diving and bowling. He's even a masterful rider in equestrian events, in which he's won numerous award, medals, and buckles.

Cynthia Fannin, Richmond's director of Education and Training, knows Anderson as well as anyone. Along with his coach, Donald Mikeska, she interacts daily with him when he's preparing for a big meet. Although David's an experienced, self-motivated athlete, Fannin helps him develop and stick to strategies for each event — including the potentially attention-sapping matters of travel and logistics.

"Every afternoon at 4 leading up to the International Games I personally met with David to discuss items on a training checklist that I made for him," Fannin said. "That was so he'd be aware of the necessary plans to make this trip happen. I also made certain he attended all telephone conferences

with the Special Olympic Committee to ask questions and exchange information about the trip.”

Along with Fannin and Mikeska, other supporters who traveled to San Juan were Richmond nurse Adelpha Castillo, direct support professional Ravon Sanders and Anderson’s buddy Malory Edwards, a fellow Richmond Special Olympian who stars in track and field.

Fannin also said credit was due to a large, non-traveling Team David consisting of Richmond staff and friends who supported Anderson in many ways. They included Mario Simmons, Cassandra Uzomah, Tom Virippan, Eilleen Holmes, Frank Rainer, Inez Espinosa, Nathan Lee, Diana Dockal, Delores Stoker, Timothy Weatherby, Robin Eversole, Jane Purcell, Donna Jesse, Valerie Ditta, Monty Chamberlain and Chris Adams. In addition, local business leaders George Boyum and Judy LaLonde with American PromoPrint donated specially designed clothing just for Anderson’s international Special Olympics competition.

But of all these supporters, Fannin said the most important may have been Edwards, a younger athlete who could relate to Anderson on the crucial jock-talk level. “They’ve traveled together to Texas Special Olympics events and our off-campus trips,” Fannin said, adding that the youthful-at-heart Anderson also shares some of Edwards’ tastes in leisure and recreational activities.

Fannin said the guys’ strong bro-bond ultimately led Anderson to select Edwards for the honor of “supporting and cheering him on during this monumental milestone in his life.”

Thanks to a combination of all this support and David’s own talent and determination, he took the silver medal in the 50-meter freestyle and a bronze in the 25-meter butterfly. Based on past performances, no one was shocked at David’s success, but Fannin said the elite competition (featuring 300 athletes from 17 countries) and the gorgeous natural setting made the trip special.

Both athletes made a point of thanking Fannin and their other supporters for helping them experience this ultimate road trip. "Malory expressed to me throughout the trip that this was the most beautiful place he'd ever visited and thanked me through the trip for a great memory and experience," Fannin said.

"David mentioned that he'd forever love me for making it possible for him to visit Diana Quirros, his friend of 26 years who retired from Richmond six years ago. She now lives in Puerto Rico and came to his competition every day. He'd just light up as he looked into the stands and saw her cheering him on."

Whether or not Anderson ever tops this peak experience, he's made a clear statement to all his fellow middle-agers that they can not only be physically vital but even accomplish athletic feats they'll remember for the rest of their lives.

Now...how about a nice low-fat smoothie and a walk in the cool autumn air?

**Quotable**

*"Be the change you want to see in the world,"* Mahatma Gandhi

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