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July 26, 2013



Speaking out for people with
intellectual & developmental
disabilities



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VOR Weekly News Update

News and views for VOR Advocates

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Reaching the Media

1. **Editorial:** Autism in the shadows
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Washington Post * July 19, 2013 * By Amy Mackin, a writer in the Boston area (see her blog at www.amymackin.com).

Several inspiring people with autism and their families were profiled on Katie Couric's show this summer. It was wonderful to see part of a talk show dedicated to educating people on what it is like to live with autism. But part of the

autism spectrum wasn't shown — the part almost never seen in mainstream media. Where are these people?

I am a parent of a child with autism, and I am lucky. My son received the support he needed when he needed it and falls into the part of the spectrum known as “high -functioning.” He has developed coping mechanisms to deal with his anxiety and sensory challenges. He has learned to tolerate some flexibility when his routine is disrupted. Most important, he is now able to share his extraordinary intelligence, his endearing personality and his unique social conscience.

My son's story is one of hope, not unlike the stories regularly broadcast on television, printed in magazines or making the rounds on YouTube.

Yet the autism spectrum is wide and diverse, and many who suffer from severe autism will never reach the level of functioning that my child has achieved. Although these people are also part of the story, we rarely hear their stories.

These people react so severely to sensory stimulation that they will seriously injure themselves as a way of relieving the stress. They are often nonverbal. Some require headphones streaming soothing music or familiar voices in their ears just to leave their regular environment for a short time.

Children and adults with autism this severe exhibit behaviors in public that mainstream society views as completely inappropriate. They mumble or yell involuntarily. They may reach out and grab a stranger's hand or stroke someone's hair.

I am not referring to people with nonverbal autism who have average or above-average IQs — those who possess the cognitive ability to communicate but whose bodies betray them.

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Computer applications and other technology can help these people communicate and do many of the things anybody else does, if a little differently.

Instead, those whose stories I'm missing do not have the intellectual ability for communication, whose IQs fall into the severely or profoundly impaired range. These are people who will never read or write or type. They will never graduate from high school; they will likely never marry or hold a job.

When I advocate autism awareness, it's this hidden spot on the spectrum that I champion.

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2. Editorial: For the disabled, Wrentham center builds true community

[*Boston Globe* * July 22, 2013 * Editorial by Colleen Lutkevich, President of the Wrentham Family Association](#)

Thank you to Kevin Cullen for the wonderful column about June Lerner, who spent most of her life at the Wrentham Developmental Center ("[The end of a 'hidden life.'](#)" Metro, July 12; see also [VOR Weekly News Update, July 19, 2013](#)). Unfortunately for the residents at the center as well as many others who are living in less-than-ideal circumstances within the Department of Developmental Services system, new admissions are not allowed, unless residents are transferring from other facilities that are closing. Without these new admissions, Wrentham Developmental Center will eventually close.

The department will not discuss this reality. It is too busy with the "community first" initiative, which mandates that individuals with intellectual disabilities, no matter how severe, be housed in a community setting. Yet too often these community settings are dangerous, with underpaid staff. high turnover. and a severe lack

of monitoring.

The Wrentham center is a wonderful community unto itself. Staff have longevity, but more than that, they have a dedication to residents and their family members that is touching, reassuring, and a great blessing when we cannot keep our family members at home with us.

It is my family's greatest hope that my sister Jean can end her days at Wrentham, her true home away from home, and that others like her can move to Wrentham as it becomes necessary for them and their families.

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3. Blog: The Arc Michigan – Our Way of the Highway

[The DD News Blog](#) * July 19, 2013 * by Jill Barker

Why is the ARC Michigan, an advocacy group for people with developmental and intellectual disabilities, having a hissy fit over two family-initiated projects in southwest Michigan? The ARC Michigan is of the opinion that if the state allows Medicaid funds to pay for services to people with DD who choose to participate in these projects, the state will be going against current trends, departing from current thinking on disabilities, and possibly violating the Americans with Disabilities Act.

This "warning" was issued in two letters from Dohn Hoyle, the Executive Director of the ARC Michigan, to the MDCH. [See links to the letters at the end of this article] The ARC Michigan receives most of its funding from federal and state government grants. [[See the ARC's 2012 Annual Report](#)]. Of course the state does not have to ask the ARC for permission before allowing the expenditure of Medicaid funds. The two family-initiated projects targeted by the ARC Michigan are [Benjamin's Hope](#) and [AACORN \(Autism Agricultural](#)

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[Community Option for Residential Needs](#)). Benjamin's Hope, near Holland Michigan, is a planned community for people with autism spectrum disorder. It is described here on the website of [LTO Ventures](#), a non-profit company that develops communities for people with autism: "A 40-acre campus designed as a community-based model to provide housing, recreation, vocation and support for 24 residents in six custom-designed homes. It is a private/public model, built with private dollars, and utilizing public funds for direct care. **They received 62 applications for the first 8 available residential slots.** The first two residences have been completed, and the community building is nearly done." [emphasis added]

Four women moved into a [licensed](#) group home at Benjamin's Hope in June, 2013.

[Here is an article from the Kalamazoo Gazette, 4/8/13, with more about AACORN Farm.](#)

It is clear that the years of thought, energy, and planning invested by these families of autistic children are approaching fruition. It is also clear that these two programs have broad community support and plans for residents to be fully engaged in what the broader community has to offer them.

So why is the ARC in such a huff?

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State News

4. New York: Sheltered workshops are in midst of a storm; Advocates for people with disabilities fear closures

Times Union (Mineville, NY) * July 20, 2013

For 20 years, V.J. Trombley has begun most of her mornings by boarding a van and traveling the 20 miles from her home in Ticonderoga to Essex Industries. where she builds cane seats

and other wooden parts for canoes such as those sold by L.L. Bean and Wenonah.

Trombley is developmentally disabled, and she works at her own pace. That's OK with her fellow workers, who also have intellectual and other disabilities. It's also OK with her employer, which is part of Mountain Lakes Services, a regional organization that serves the disabled.

"I love it here," Trombley said.

She's one of almost 8,000 people in New York state who work in 115 sheltered workshops, or closely supervised settings where their differences are accommodated.

The Essex Industries shop was humming along during a recent visit, but there's a good chance in the next several years it will be as silent as the iron mines that once dotted this region of northern New York.

That's because the state Office for People With Developmental Disabilities has told operators that their funding is being phased out — a product of federal funding reductions, legal challenges against such workshops in other states, and pressure from Washington D.C.

Workshop operators have been told to stop accepting new participants as of this month.

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5. New York: State Rewards Home Care Firms Once Rebuked

***New York Times* * June 24, 2013**

Hunting for ways that the incoming governor could close a \$2 billion budget deficit late in 2010, New York State officials scrutinized Medicaid spending on home health care, and made some startling discoveries.

The cost of caring for frail elderly and disabled people at home had more than doubled from 2003 to 2010, to \$1.3 billion, even though fewer people were being served. And that huge cost increase had been driven by just a half-dozen certified home health agencies out of 140. most located in Brooklyn.

Two names stood out: Excellent Home Care and Extended Home Care. During a broad investigation of Medicaid fraud he conducted as attorney general, Gov. Andrew M. Cuomo had showcased his role in reclaiming \$3.7 million from Excellent and \$9.5 million from Extended in a settlement of false-claims suits against them. The agencies admitted no wrongdoing.

Now a transformation of the state's long-term care system is in high gear, as the state has extended invitations to agencies to be a part of the new system. Among those chosen: Excellent and Extended.

"I don't know what an organization would have to do to be disqualified," said Susan Regan, a longtime member of the state's public health planning council who was outraged to discover, on Page 221 of a meeting agenda, that the Health Department had endorsed Excellent for an expanded license.

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Legal News

6. US sues Fla. over disabled kids in nursing homes

Associated Press *July 22, 2013

MIAMI (AP) — The U.S. Justice Department filed a lawsuit against Florida on Monday, accusing the state of unnecessarily institutionalizing about 200 disabled children in nursing homes and cutting services that would allow them to receive care at home.

Federal investigators visited six nursing homes around the state and identified about 200 children they said didn't need to be there and could benefit from care at home or elsewhere in the community. The investigators found that once in the facilities, many children stay for years, some growing up in the nursing homes.

Parents say they have no other option

because the state has slashed in-homes services, including nursing care for critically ill children on ventilators and feeding tubes.

Investigators said Florida is violating the federal Americans with Disabilities Act and infringing on the children's civil rights by segregating and isolating them. The average length of stay is three years, federal officials said. Many of the children are physically disabled but mentally cognizant.

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Quotable

"For families living with a severely disabled family member, a utopian vision of the world where everyone, regardless of the severity or nature of their disability, can live independently, engage in competitive employment, and live fully integrated lives in "the community" (whatever that means), makes as much sense as a vision of a world where severe disabilities don't exist at all. We need realistic solutions, not over-simplified utopian notions that only serve to limit the range of choices. Creative family and community-based projects that provide specialized services and residential options to people with DD should be encouraged, not prevented from getting the assistance they need to succeed." ~ Jill Barker, [DD News Blog](#)

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Calendar Reminders:

* **How Congress Works Webinar: [Recorded - Listen Here](#). Tuesday, April 23, 2013 - 12:00 pm central / 1:00 pm eastern**

FREE WEBINAR: How Congress Works: The Basics. Hosted by Peter Kinzler and Larry Innis.

* **AHCA/NCAL to host Intellectual and Developmental Disabilities (ID/DD) Day – October 6, 2013. [Details online](#).**

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