

Newtowners Are Not Invisible In Advocating For Disabled Services

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By John Voket



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Lynn Willie of Newtown stands beside her son, Jay C, in the lobby of the State Capitol. The two joined a rally of about 100 supporters November 24, calling on Governor M. Jodi Rell to support parity in funding for private group homes and care facilities for individuals like Jay C who are developmentally disabled. The Willie family and the Letso family are Newtown neighbors, and they share a common concern. Both families hope their developmentally disabled sons will receive the kind of quality care and support they deserve as they age — especially after their parents have died, or themselves have aged beyond the point of providing care if their children are ever forced from their group home settings.

But hope is where it ends.

Because both families are acutely aware that the kinds of private group homes and institutional organizations caring for their children, and more than 16,000 others here in Connecticut, are facing monumental challenges. Challenges that could force a legion of developmentally disabled clients back into the homes of their parents or siblings, onto lengthy waiting lists for state agency placement, or in the worst cases, out onto the street.

Both the Willie family: mother Lynn, father Jay, and adult sisters Jina and Jaime; and the Letsos: mother Suzanne, father Roger, and sister Meredith, are standing with the parents, siblings and caregivers of those tens of thousands of disabled sons, daughters, brothers, and sisters who cannot advocate on their own behalf.

On November 24, Lynn Willie and her 25-year-old son Jay C were among more than 100 people who marched on the Capitol in Hartford as part of a grassroots movement called We Are Not

Invisible (WANI). The contingent bundled up and assembled that chilly morning hoping Governor M. Jodi Rell would grant them a meeting.

The organization is appealing for parity in funding for private and nonprofit agencies, whose compensation for providing care for disabled adults pales in comparison to state institutions like the now-defunct Fairfield Hills State Hospital, and neighboring Southbury Training School. The WANI supporters believe, based on data they have assembled, that private organizations like the Trumbull-based Kennedy Center and Bethel's Ability Beyond Disability could provide equivalent care for two disabled clients for the same money taxpayers spend to provide care for a single resident in a state-run institution.

Martin Schwartz, president and CEO of the Kennedy Center, recently produced a column for the media in which he discusses the issue from his perspective. He writes, "Presently, the core of our state's network of high-quality, private nonprofit organizations supporting people with intellectual disabilities (mental retardation) is being eroded by chronic lack of adequate funding." The Kennedy Center, which operates a day program in Newtown, serves more than 1,500 people with disabilities, providing therapeutic and educational support to job training to community independence and transportation. The organization currently employs 550 individuals and depends on added support provided by more than 400 volunteers.

Why Is This Happening?

Mr Schwartz lays blame directly on "the repeated underfunding of private social service agencies by the state of Connecticut" that is putting community-based agencies like his serving people with developmental disabilities at dire risk of closing.

According to Mr Schwartz, the Consumer Price Index has increased by more than 80 percent in the past 20 years while increases in state funding to community providers has been less than 30 percent.

Since 2004, he says the state of Connecticut has provided the Kennedy Center with inconsistent and incremental cost-of-living adjustments ranging from zero percent to four percent. And this year, no such increase was budgeted.

"How can our employees survive without even a modest raise during this time of economic chaos?" Mr Schwartz asks. "As the cost of health care and energy continues to escalate, we cannot ask our employees to live on even less money than they already are."

The cruel irony for Mr Schwartz, and families like the Willies and Letsos, is that private providers serving the developmentally disabled ultimately save the state of Connecticut nearly \$2 billion a year by delivering 80 percent of the services.

There are more than 19,000 Department of Developmental Services clients served by the state and the private sector in Connecticut's bifurcated delivery system. The state directly serves approximately 20 percent of this caseload at an average annual cost of \$102,338 per client, versus the total cost of \$29,081 for each private provider client.

"This amazing cost differential should certainly sound a loud alarm of warning to everyone, for if the private provider community comes crashing down, the state will be left with a new budget hole to fill equating to more than \$1.1 billion," Mr Schwartz stated.

Private Care Choice



[Enlarge image](#)

Jay C Willie, formerly of Newtown, stands outside the State Capitol November 24, lending his voice to calls for increased funding for private and nonprofit organizations that care for Connecticut's developmentally disabled.

Ms Willie's experiences with private sector care began after Jay C graduated from Staples High School and began his day program through Ability Beyond Disability four years ago.

"We accepted a state waiver and he remained on the waiting list for a group home," Ms Willie told *The Bee*. "Through hardworking efforts, letter writing to the governor, the state commissioner, the private provider we chose, and phone calls, Jay C was finally placed into Ability Beyond Disabilities' group home in Prospect.

"We felt very relieved that he is safe and his needs will be met in the event we should no longer be around, and he wouldn't be a responsibility of our girls," she said.

In the wake of this year's financial sector debacle, the Willies learned about the financial crisis affecting not only her son's placement in a private sectors group home, but every child and client served by private providers.

"I am learning of a system that is broken, and needs great attention," Ms Willie said. She has come to learn that Connecticut's Department of Developmental Services serves 20 percent of

the population, but receives 50 percent of the budget while private providers "serve 80 percent, very efficiently" with the other 50 percent of the budget.

She and thousands of other caregivers, including the Letsos, have lent their energy to WANI; they have already delivered 6,000 signatures on petitions to the governor requesting she help provide adequate funding for the private network providers, and have held two separate rallies at the Capitol to date.

The Letsos founded the Connecticut Center for Child Development (CCCD) in Milford after several frustrating years trying to obtain acceptable educational opportunities for their son Tyler, who is autistic. CCCD became the first school in Connecticut that used evidence-based learning principals known as applied behavior analysis to positively impact the educational experience and lifestyle of its students and their families.

Ms Letso said she plotted a hypothetical financial outcome based on a salary she would have received if she was paid at the state's rate of compensation for a private provider.

"If I started collecting the state's rate of compensation in 1987, by 1998 I would have been losing money and by 2001, I would have been bankrupt," she said. "By trying to save a little money now by not giving adequate cost of living increases, or providing adequate compensation to private community providers, will result in belt-tightening among these agencies. In this economy, it could force some to close or cut back on the number of individuals they serve, which means many will be forced into state-run care environments that cost taxpayers a lot more."

Anyone wishing to sign a cyber petition in support of increasing state funding for private providers, or to learn more about We Are Not Invisible, can click on www.wanict.org. Other resources and information are available through the Connecticut Community Providers Association at www.ccpa-inc.org.