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### CAN TRAINING SCHOOL BE USEFUL?

*STATE WANTS IT SHUT; OTHERS SAY RETOOL IT AS OUTPATIENT CLINIC FOR DISABLED; FUTURE OF SOUTHBURY CAMPUS*

Hartford Courant - Hartford, Conn.

Subjects: Developmental disabilities; Disabled people; Federal funding; State employees

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#### Document Text

Arthur Roberts and Jenna Herbst have taken different paths to reach a level of comfort.

Some would say that Roberts, 67, and Herbst, 37, represent the past and the future of the way people with developmental disabilities are supported and treated in Connecticut.

Roberts lives with round-the-clock care at Southbury Training School, the largest remaining state facility for those with intellectual disabilities. Herbst lives in an apartment with the same level of support.

Roberts has a job shredding paper and a pleasant room filled with family pictures and boxes of Matchbox racing cars. His family drops in at will and whisks him off to different places, restaurants, parks and the like. Herbst has Bridgeport Bluefish baseball tickets, goes to high school wrestling matches and to church on Sundays, and has, her father said, an active, vibrant life, although she is totally dependent on others for her daily living.

Roberts and his mates at Southbury are the last generation of residents there. The sprawling 1,400-acre campus is on track to close.

Although the end is still years away, the state is resolute in its commitment to maintain a freeze on new admissions at the facility, which is expensive to run and provides what some consider an obsolete model of care.

Some advocate that part of Southbury be retooled to serve a portion of the population on an outpatient basis, using the expertise that exists on campus. A recently opened dental clinic quickly drew more than 430 patients who come to the campus three times a year for treatment.

#### SWEARING BY SOUTHBURY

There is a desperate need in Connecticut for services and support for people with developmental disabilities -- including a list of more than 1,000 people awaiting emergency or priority treatment. Further intensifying the need are deficiencies in the wider system of care, which includes state facilities, public and private groups homes, and nursing homes. Over the past decade, for instance, the deaths of dozens of people in the system have involved neglect, abuse, or errors in health care.

The cost of care at Southbury remains staggering: More than 950 state employees serve 368 residents, at a price tag of \$380,000 per resident, per year.

In contrast, the cost for Jenna Herbst's care is about \$154,000 per year. About \$140,000 of that is state and federal funding, said her father, Mickey Herbst, a retired printer from Westport.

The Southbury campus has a large roster of dentists, doctors, psychiatrists, therapists and health aides experienced in the treatment of people with developmental disabilities. At the same time, many professionals in the community are hesitant to treat this population, either because the Medicaid reimbursement is too low or they lack familiarity, or both.

Against this backdrop, Southbury families and guardians, who swear by the services their loved ones receive on campus, are pushing to establish a multi-disciplined health clinic with existing resources to serve developmentally disabled people statewide. Such a project, the families say, would build on the success of the dental clinic, which quickly filled a widely acknowledged void in community care.

One advocate who has worked to close Southbury noted the clinic's early success and said the general state of dental care in the community for intellectually disabled people "is horrible."

But the stigma of Southbury's past -- overcrowded wards and federal lawsuits over conditions -- appears to be too great. There is no political momentum to do anything there but keep the promise made to the Southbury families that none of the residents will be moved out against their will.

"The Southbury campus is poisoned," said one influential legislator.

Though its 125 buildings on a 1,400-acre campus are gradually closing as they empty, and the sprawling property is being consolidated, the campus will remain open in some form for years to come.

An internal memo at the state Department of Developmental Services projects that between deaths and placements into the community, 69 residents will remain at Southbury in the fiscal year 2020-21.

Martha Dwyer, sister of Southbury resident Tom Dwyer and head of the Southbury Home & School Association, said that in addition to the dental clinic, an upgrade of the on-campus health care facility that serves residents resulted in more than \$1 million in increased Medicaid billings for the state in 2012. She said it's pure madness that the campus resources are not used to benefit intellectually disabled people around the state.

"You serve people in need and you spread the cost of operating Southbury," said Dwyer.

She said that state funding for private group homes has been flat over the last five years, and that some of those homes are going under. She also said the state is selling off its own group homes, a trend that only increases the need for high quality health care and an array of other services outside of the family home.

#### 'IT'S HIS HOME'

The Southbury campus, once the home of nearly 2,000 people, has been under some form of federal court oversight for decades, and admissions have been frozen since 1986.

The 1970s and 1980s were dark decades for Southbury. Overcrowded and understaffed, some wards had as few as two workers for as many as 60 residents, said Paul Fortier, an organizer with Local 1199 of the Service Employees International Union, which represents the workers at Southbury.

"That Southbury should have closed," said Fortier, who worked there in the mid-1970s and early 1980s.

But by 2009, Senior U.S. District Judge Ellen Bree Burns ruled that the state, by improving conditions at Southbury, had satisfied the requirements of a lawsuit filed by the U.S. Department of Justice 25 years earlier.

In 2010, Burns approved a settlement in another lawsuit, *Messier v. Southbury Training School*. The agreement required that the state provide services to the intellectually disabled population in the most integrated setting possible, and that residents at Southbury and their families and guardians be continually informed of all alternatives and options to Southbury.

There were 22 community placements in 2011 and 2012, and 25 Southbury residents are projected to move into neighborhood-based group homes, or return home with added support services, this year, according to a DDS internal memo.

Many of the families and guardians of the remaining 368 men and women at Southbury are fighting all the harder to preserve the campus and return it to relevancy. They say the level of care and expertise -- doctors, nurses, psychiatrists right there on staff -- cannot be equaled at group homes with high employee turnover rates and shared, on-call nurses.

While the thrust now is for the "mainstreaming" of people with intellectual disabilities, when the Southbury families had to make decisions about what to do with loved ones 30, 40, or 50 years ago, few, if any, other options existed. The average age of the Southbury residents is about 64.

"It was the most painful decision my parents ever made," said Ann Dougherty of Southbury, whose brother, Michael, has lived at the campus for 64 years. He came there as a 5-year-old.

"It's his home," she said.

"People here have 26 years experience with my daughter, Susan," said Marylyn Hendricks of Warren. Susan Hendricks, now 46, came to Southbury at age 12. She has Rett syndrome.

"The doctor knows how to care for her. This has been my daughter's home and community for her life," said Hendricks.

Arthur Roberts has been at Southbury for nearly 40 years. He lived at home with his family in Winsted until he had a psychotic breakdown and could no longer remain at home, said his sister Barbara Hirsch, a retired registered nurse.

As a child, Roberts attended a school formed by Hirsch's mother and another woman, but his life became more difficult as he grew older, Hirsch said.

"He failed at a factory job even though he had a job coach. He failed at a group home. He ended up medicated, at Fairfield Hills State Hospital, and then came to Southbury. He has a dual diagnosis. He has the intellectual ability of an 8-year-old child, and is manic depressive and schizophrenic. He cycles, has his good periods, and his bad. I don't want him in a nursing home and I don't want him in a group home. Our choice, always, has been that he stays at Southbury."

#### 'VESTIGE OF THE PAST'

Along those lines, the state Department of Developmental Services is rapidly shifting its focus to home- and neighborhood-based services. In the jargon of the federal regulators who are closely watching Connecticut, Virginia, and other states, accommodations for people with intellectual disabilities must be in the "least restrictive" and "most integrated" settings possible.

DDS Commissioner Terrence Macy said that for every person at Southbury, there is a "developmental twin" receiving equal services in the community.

"In this regard," Macy said, "institutional settings are a vestige of the past."

He said that the feds are working on a new definition of a "community" -- one that he expects will reclassify any facility with more than four beds "as an institution" that is "not reimbursable through federal funding."

Macy said there "are no plans for an expanded use" of the Southbury campus. He said the new federal definition of "community would be considered in any discussion of [Southbury's] being reused as a statewide geriatric setting or medical facility."

But there are immediate concerns in Connecticut about a shortage of public money for any sort of services, home-based or otherwise. And there are inconsistencies in the quality of care across the landscape of state facilities, private group homes, nursing homes and even family homes.

A Courant series in March chronicled 76 deaths involving abuse, neglect, or errors in health care from 2004 to 2010. Twenty-two other suspicious deaths were investigated, but no finding was reached. Large facility or small, public sector or private -- no aspect of the system was immune.

After the series ran, U.S. Sen. Chris Murphy, a Connecticut Democrat, called for a national investigation of services for developmentally disabled people, with an emphasis on preventable deaths in private group homes.

Murphy recently expanded on his position.

"We have a national problem in providing access to health care for people with intellectual disabilities," he said. "In particular, in Connecticut, it is very hard to find a dentist who will take a developmentally disabled patient."

He said that is, in part, because Medicaid reimbursements are too low.

#### WAITING FOR HELP

As of last September, the Department of Developmental Services was reporting a waiting list of 1,022 developmentally disabled people who needed emergency or priority care.

Fortier, the union official, cited this waiting list, as well as the 300 people with developmental disabilities now in Connecticut nursing homes, as evidence of a pressing need for expanded medical and health services. He said the Southbury campus should be considered as a location.

Fortier said the union would support the transfers of Southbury workers to other state jobs as the residential population on campus decreases. He said that the union supports home-based and neighborhood-based services for intellectually disabled people, and that reopening the Southbury campus to admissions was probably not going to happen.

With regard to nursing homes, Macy, the DDS commissioner, has said that the agency's clients do not belong there, in large part because those facilities and their staffs are not always equipped to handle the needs of intellectually disabled people. He has said that group homes serving DDS clients should be prepared for the residents to "age in place."

But that is not the case now for most group homes that contract with DDS.

Fortier said Connecticut "needs a rational plan for the placement of the people in the nursing homes and those on the waiting list."

He added that there is also a "desperate need" in the state for short-term respite care of intellectually disabled people, so that their caregivers at home can have a break. He said Southbury "could be re-imagined" as a place that provides short-term respite, geriatric and medical care.

Leslie Simoes, executive director of The ARC of Connecticut, the state's largest advocacy group for people with intellectual disabilities, shares the view that services urgently need to be expanded, but she is strongly opposed to using Southbury to do that.

DDS "has a billion-dollar budget and serves 20,000 people," said Simoes.

"I get calls every day from people, aging parents wondering who will take care of their 50-year-old son with Down syndrome when they die. For some, dropping a loved one off at the emergency room is the only way to get services."

Macy said that there is no money for added medical services at Southbury and that he believed geriatric services geared strictly for the intellectually disabled would be considered a "segregated setting" and be prohibited.

Despite his position on nursing homes, he said that as long as there are empty beds in those facilities, he doesn't believe the state could demonstrate the required level of need for statewide geriatric services at Southbury.

Credit: JOSH KOVNER, jkovner@courant.com

Illustration

PHOTO 1: (B&W), COURANT FILE PHOTO PHOTO 2: (B&W), BRAD HERRIGAN | BHERRIGAN; Caption: PHOTO 1: THE CAMPUS of Southbury Training School, with its main buildings overlooking Route 172 in Southbury, has 125 buildings on 1,400 acres. PHOTO 2: ARTHUR ROBERTS has been a resident of Southbury Training School for more than 30 years. His sister Barbara Hirsch wants her brother to stay there, though the state has frozen admissions at the facility for people with developmental disabilities and intends to close it.

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Abstract (Document Summary)

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