

# **Ageing parents worry about the future of their developmentally challenged children**

**How will children survive when caregivers are gone?**

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For the aging parents of adults who have developmental disabilities, the conditions at an unlicensed rooming house recently shut down in Buffalo represented their worst nightmares.

Sewage backed up in the basement. Windows were boarded up. Someone piled torn plastic garbage bags outside a rear door. Rats infested the house.

Eight residents living in that squalor were down-and-out adults, several of them developmentally challenged, others physically disabled.

And they didn't want to leave. They didn't know how to find anyplace better.

Once parents or other family members can't take care of their disabled offspring, the disabled adults are at the mercy of others who may not provide a good place to live.

"We worry about waking up dead," said Barbara DeLong, the mother of a severely disabled young woman who is aging out of the school system. "And what is happening out there is not acceptable."

City police, housing inspectors and a City Court judge moved to close the illegal boardinghouse on East Utica Street.

The eight residents were receiving help through Erie County's Adult Protective Services program. What happened to them shows how much more support they needed.

DeLong and other parents are now lobbying state government to provide more money for additional community placement homes and other services. They want their adult children to transition into safe, supportive settings while their parents are still alive and able to help ease the process.

The U.S. Supreme Court in 1999 ruled that placing disabled adults in institutions is unacceptable. The parents agree, but they hold strong views on how to proceed with the policy of moving developmentally disabled people out of large state institutions.

New York has responded to the federal mandate by coming up with a process to provide services for the developmentally disabled in the most socially integrated setting appropriate to a person's needs.

The goal is to keep individuals in private homes or in group homes when possible. Others could live in apartments or rooming houses with supervision and support services, ranging from around-the-clock support to a less-comprehensive approach.

The changes might save money in the long run, but they cost money to implement.

Statewide, advocates for the disabled are looking for an additional \$30 million in the state budget to add more group home beds.

Among those taking their case to Albany are the families of the Developmental Disabilities Alliance of Western New York, an advocacy and support group for family members of people with disabilities. Its members contend that current funding is grossly insufficient to meet the need that exists and is growing.

More than 306,000 people in New York State have developmental disabilities, including those with Down

syndrome, brain injuries or on the autism spectrum. Almost two of every three of them – 195,388 – live at home with other family members as caregivers.

Of those living at home, 49,673 have caregivers who are 60 or older.

Meanwhile, more than 12,000 people statewide – including more than 1,000 in Western New York – are on a waiting list for placement in a group home or other community housing.

Current state plans would fund 530 new group home beds during this fiscal year and 500 more in 2016 and 2017 – not enough to accommodate the existing waiting list and a fraction of the housing that advocates predict will be needed.

The state plan to mainstream most disabled adults into regular employment and independent living is overly optimistic, and doesn't take into account the reality of their disabilities, some family members say.

More than two dozen members of Developmental Disabilities Alliance of Western New York took a bus to Albany recently with some of their disabled sons, daughters and siblings to urge state lawmakers to provide the funding.

“We wheeled them in,” said Fred Henssler. “You don't like to ‘showcase,’ but we put the problem right in front of them.”

The situation has another effect on the parents who for years have held tightly to the signs of progress they see in their children. Now they have to learn to ignore those moments. The less their children are capable of, the more likely it is that they will get help.

“Make sure (their assessment) it realistic,” Henssler said. “We've all been taught that we want our children to be high achievers, but being able to do something once or twice a month doesn't cut it. If they can't do it all the time” – walking, dressing themselves, eating independently – “they can't do it. Stick to your guns. Don't paint a rosy picture.”

Many of these adults will not be able to work. They will not be able to find housing for themselves. And they will not be able to seek out medical care, transportation or other basic needs on their own, the alliance families say.

The situation has parents in emotional states that range from anxious worry to near panic as they see loved ones in need of services languishing on waiting lists.

“We are in a crisis,” DeLong said.

Her daughter, 20, was not expected to live past infancy. She overcame the odds and has been able to interact with others, walk a little and eat with help. DeLong says she still celebrates every time she can get her to do something as simple as eat some yogurt.

“The state really wants most of the people receiving services to be ‘self-directed,’ ” DeLong said recently to a group of alliance members. “I hear the chuckles.”

Rhonda Frederick, chief executive officer and president of People Inc., which provides services for the disabled and others, sees some good news on the funding front.

Federal grants have been awarded to several local agencies, including People Inc., to come up with plans for transferring sheltered workshop employees into jobs in the community and to ease those workers into managed care situations.

The concern, she said, is making sure that their care really is managed.

“This is not a group that makes friends easily,” Frederick said. “Outside of group care, they can suffer from

social isolation and loneliness to an extreme degree. They lose the socialization environment that helps them succeed.”

They’re like the people in the boardinghouse that was closed down earlier this month.

After the tenants were relocated, Erie County spokesman Peter Anderson made it clear that those under the care of Adult Protective Services cannot be told where to live.

However, he added, “Adult Protective Services will be scrutinizing the health and safety of all clients under their care.”

City Court Judge Patrick M. Carney and Chief Building Inspector Louis Petrucci also made it clear the issue is on their radar. Carney said he will do all he can to crack down on owners of substandard rooming houses, and Petrucci said his office plans to work more closely with Adult Protective Services.

“We want to make sure that people who can’t advocate for themselves are living in safe conditions,” Petrucci said.

Meanwhile, families wait to see what happens with the state budget.

“We get older, our kids get stronger and we are more stressed,” DeLong said.

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