

## A Painful Choice Over the Mentally Disabled Dearth of Group Homes Leads Dozens Of Families in Northern Va. to Send Their Loved Ones Far Away for Care

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It was a decision that Peggy Kube thought she would never have to make: Her brother, Terry Leatch, a 50-year-old with severe mental retardation, needed a new group home with more supervision. He wanted to stay near his sister because their parents, who doted on him for years, were dead.

But there was no place for him near her Spotsylvania County home -- not in Fairfax, not in Loudoun, not in Prince William. So she did the once unthinkable and had him moved 200 miles from his sister "Peg" to a group home outside Lynchburg, Va.

"I can't imagine that this is what my parents ever wanted for him . . . being so far away from family after we tried for so long to have him near us," said Kube, 61. "They were focused on family, keeping our family together the best way they could."

Like Kube, several dozen Northern Virginia families have sent mentally disabled relatives to facilities hundreds of miles away over the past few years because there is no space for them at the area's few homes. Escalating land, labor and other costs have prevented enough homes from opening at a time when the region's population and health-care needs are rising.

Virginia has long had a poor reputation for caring for the mentally disabled, and the problem is particularly acute in its suburbs outside Washington, local officials said.

Nearly 1,400 Northern Virginians with mental disabilities get a Medicaid-funded waiver to receive services -- largely group home beds -- in the community in lieu of being placed in institutions. But because of funding shortages, nearly as many are on years-long waiting lists to receive this community care, which is cheaper than placing the mentally disabled in the large facilities downstate.



Peggy Kube of Spotsylvania had to place brother Terry Leatch in a group home outside of Lynchburg because there were no spots available near her. (Photos By Jahi Chikwendiu -- The Washington Post)

A 2004 University of Colorado report found that Virginia was 47th in the nation in funding for the mentally disabled.

As a result, the rare instance of a new Northern Virginia group home opening often follows one closing, advocates and local officials said. In addition, several agencies have scaled back operations to cut costs and stay open.

Gov. Timothy M. Kaine (D) included money for 170 more group home beds throughout the state in the budget he proposed Friday. But he did not include a \$5.5 million annual increase that Northern Virginia providers had sought to help defray the higher costs of doing business in the area.

For families, the lack of facilities creates heartbreaking decisions and strained relations as visits become less frequent.

To health-care advocates, the situation makes no sense. For years, they have tried to move the mentally disabled out of large, distant facilities into smaller, community-based ones near family.

"It's been like we've taken two steps forward and are now taking four steps back," said Nancy Mercer, executive director of The Arc of Northern Virginia, an advocacy group for the mentally disabled. "We're undercutting the ultimate point of our system, which is to provide community care for people to live in their communities."

Mercer and parents of the disabled said that it is crucial to keep vulnerable children nearby to provide better care and to keep them in the kind of familiar settings that can ease their lives.

"We've seen a screeching halt of new development for residential providers in terms of their ability to grow and expand because for years the [state reimbursement] rates haven't kept up with the cost of doing business," said Alan Wooten, director of mental retardation services for the Fairfax/Falls Church Community Services Board. "When you have a shift like this, it creates hardships on the families because they are no longer able to provide some natural supports and visitation."

At the same time that beds in Northern Virginia have been unable to keep pace with demand, a rising number of group homes have opened elsewhere in the state, including in the Appalachian southwest and Shenandoah Valley, where costs are far lower. For instance, this year, Northern Virginia received about 25 new slots for group homes, but that put only a small dent in the waiting list of more than 1,000 in the region, activists said.

State officials said they are generally aware of the decisions many Northern Virginias have to make about group home placements and acknowledged that they have not set up specific programs to address the issue. Several said that in some cases, living away

from parents should be an option for the disabled just as it should be for those without disabilities.

"It's certainly a complex situation. But if the adult child wants to stay near their parents, and the parents want the child there, it would be good to do that," said Paul R. Gilding, director of community contracts for the state Department of Mental Health, Mental Retardation and Substance Abuse Services. "But unfortunately, sometimes that can't happen."

Advocates and state officials in Maryland said that, as in Virginia, there are waits of several years for similar services but that they aren't aware of families having to send relatives far away, partly because the state is smaller. Advocates in the District said they are not aware of disabled adults being placed in group homes elsewhere, either.

Activists in Northern Virginia estimate that 70 families have sent mentally disabled adult relatives elsewhere since 2001.

Edith Brinkley, 83, of Fairfax County sent her son Jay, now 53, to a Harrisonburg group home a few years ago because a small facility in the county was closed. The Shenandoah Valley group home was the only place that could meet his needs. She characterized the decision as a devil's bargain of sorts -- balancing the needs of keeping her family members close with the only options they had.

"Of course we want what's the best for my son, the best care," Brinkley said. "But it's important for him, for us to remain together. I thought that's what we've been fighting for all these years."

Jay has been gone for four years, she said, and she visits only once a month, when her daughter drives her the 120 miles.

"It just isn't the same," she said.

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