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When care can't wait but it does

How families of the developmentally disabled are coping

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For all of her 32 years, Holly Van Hart has required constant care.

She's like a toddler — sometimes good, sometimes terrible.

And recently, violent.

Holly attacked her mother with a wrought-iron wine rack, bruising her, and pulled out clumps of hair.

"I had to call 9-1-1," said her mother, Phyllis.

Holly and Phyllis, 54, have lived a rollercoaster life together, but Phyllis always coped.

Now, Phyllis is at wit's end.

The Endicott mother had two chances more than five years ago to put Holly in a group home.

Now, even if she can bring herself to do it, a spot in a government-funded home no longer may be an option. Some families already have to wait years for placement, and no new homes are on the horizon as the state struggles with a tenuous fiscal situation.

The lack of spaces may create more of a challenge in coming years as baby boomers such as Phyllis are no longer able to care for their developmentally disabled family members.

More than 125,000 people are eligible for services overseen or certified by the state Office for People With Developmental Disabilities.

In the Broome Developmental Disabilities Services Office's area, which includes Broome, Chenango, Delaware, Otsego, Tioga and Tompkins counties, there are 418 group homes that serve 1,146 people.

As of July 8, the Broome agency had 264 people awaiting placement.

The developmentally disabled have mental or physical conditions such as autism, cerebral palsy, epilepsy or Down syndrome. Limited mobility can be a major issue, as can an inability to tend to their personal needs, to express themselves, or to learn normally.

The state agency is charged with supporting those individuals in ways that allow for as many as possible to access vital supports and services. But the OPWDD mission is at direct odds with the state's financial realities.

Gov. Andrew Cuomo is working to reform Medicaid, which funds most care for the developmentally disabled. The OPWDD, too, is scrutinizing its service structure in its \$4.3 billion budget. That money supports many programs, including more than 39,000 spaces in group homes run by the OPWDD or nonprofit agencies statewide, a number that's higher than last year but still less than what's needed.

"It's frustrating for families. It's frustrating for us," said Christine Washburn, lead services coordinator for the Handicapped Children's Association, which runs 10 group homes in the Binghamton area and a variety of services for the disabled. "We have families leave and move to another state to get services. And that's unusual because people moved here for services."

No one is denied services. Instead — particularly in terms of group home placement — they're put on sometimes years-long waiting lists until a spot opens or a crisis forces action.

"Unfortunately, there are some cases when a person can't remain at home," HCA Executive Director Stephen Sano said. "We do the best we can to try to find a space."

Paula and the Rev. Mark Giroux of Whitney Point put their autistic daughter, Marie, on the waiting list in 2000. Four years later, a spot opened. Now 27, Marie lives in an HCA home with two people who also need constant attention.

The group home environment has expanded Marie's horizons. She participates in activities Mark and Paula would have considered unthinkable, such as sitting through movies or being calm in a crowd.

"It's hard to know we can't take care of her the way she should be taken care of," Paula said.

They are thankful theirs was a relatively short wait to get Marie into the facility, Mark Giroux said.

"It's hard for families to fathom, when they need it, that they have to wait," he said.

First priority for placement goes to people facing abuse or neglect, who are in danger of being homeless, or who present an imminent danger to themselves or others.

Second priority goes to people with aging or health-compromised caregivers, whose medical or physical condition requires care unavailable in the present situation, who present an increasing risk to themselves or others, or for whom the courts or legislative mandate requires residential placement.

People who aren't facing danger to their health or well-being or that of their caregiver are considered third, or non-urgent, priority.

The number of group homes grew tremendously over the last decade, allowing the state to close developmental centers in the Finger Lakes region and Buffalo.

Now 62, Meredith Thomes made that transition from institution to an HCA group home in Dickinson.

When she was 14, she was sent to Letchworth Village Developmental Center in Rockland County as a result of brain injury from childhood encephalitis and seizures, she said. She spent decades housed in situations far different from the one she's in now.

"I like this place," Thomes said of the group home. "We go on picnics and trips and stuff like that. We volunteer. We work in Community Options on State Street. Sometimes we do arts and crafts."

After Thomes and others transitioned to group homes, the state's fiscal crisis took hold and development of other group homes was halted.

"We were developing two a year for many years," Sano said. "It doesn't happen that way anymore."

As bad as the numbers are now, and if the quantity of newly-diagnosed children with autism is any indication, the need for residential facilities will be still greater in the decades to come.

Brenda Rohena appreciates her group home.

Cerebral palsy forces 21-year-old Rohena to live her life mostly from a wheelchair. Bubbling with the energy of youth, she savors days spent at a summer camp run by ACHIEVE, another local service provider, and lives at a home run by HCA.

She and her five housemates enjoy individual weekly outings.

"They just can't stay in the house or go to programs; they need to do something out in the community," said HCA behavior specialist Goretti Mugambwa. "We would have serious behavior problems if they got bored and frustrated."

Jon Vieux, now 72, lives in an ACHIEVE group home on Main Street in Binghamton. He's very social, said his sister Judy Vieux, and he still goes off to work every day at Country Valley Industries on Lester Avenue in Johnson City. He also goes to church twice on Sunday and every Wednesday night.

For those who can't get into group homes, care falls to the family. But even the most dedicated caregivers won't live forever.

Melvin Williams has lived all of his 52 years with his mom and dad, Mitzi and Tom, on the East Side of Binghamton. Mitzi's not sure how much longer that can continue, though. It's not Melvin's Down syndrome that's the problem. It's her health.

She's 77, and Tom's only two years behind her. She worked at the Broome Developmental Center as youth program supervisor and he's retired from the Town of Dickinson Highway Department.

Now they're starting to feel their years.

"We thought of making a placement in a group home, but figured as long as we could take care of him, we would. He's cooperative, very easy to get along with," she said.

His five siblings were always protective of him. "His brother would get in fights when kids called Melvin names," she said.

They'd take him to the library with him, and he'd pick up a book and pretend to read.

"He's been more pleasure than pain," she said. "He has taught us so much about patience, tolerance and acceptance."

He and longtime friend, John Husnay, participated in Special Olympics together when they were younger. Now they work together at ACHIEVE.

His sister Deborah will take care of him when Mitzi and Tom can't anymore. Her house is big enough, but she's not sure having him with her is the best solution.

He goes to work every day but she thinks more socialization might be better for him.

"Sometimes I think it's more about us," Deborah Williams said. "Not wanting to let him go."

The government covers most of Melvin Williams' expenses, but that's not true for all families.

Some services that families seek are covered by insurance. Mary Ann Egan of Johnson City estimates she and husband Paul spent in excess of \$60,000 out of pocket to give their son Ryan the best treatments possible for his multiple disabilities, including hyperbaric oxygen treatments and Botox injections to ease the spasticity caused by Ryan's cerebral palsy.

Without insurance and state support, that number would have been significantly higher, she said.

Now 18, Ryan has always lived with his parents, but Mary Ann knows that may have to change someday. Ryan has no siblings, and his aunts and uncles are willing, but also aging.

"You get all these ideas," she said. This fall they'll scout out Camphill Special School, near the home of a relative in Exton, Pa., where Ryan would live and work to help grow his own food.

"We've thought of buying a town home and having somebody on the other side live with him," she said, "and ideally with another special-needs adult as company."

Get involved

For all families with developmentally disabled loved ones, involvement is critical. Families need to get their loved one registered with the OPWDD — the earlier, the better — to determine eligibility if they want to take advantage of services at a later date.

Topics to consider are the individual's living options, interests and socialization needs, employment or vocational needs and financial requirements, OPWDD spokeswoman Nicole Weinstein noted. Planning can help avert a potential crisis in the future.

"Families can help themselves by making sure early on that their loved one is connected to the system," said ACHIEVE executive director Mary Jo Thorn.

Eligibility isn't the same as entitlement.

Robert Stack, chief executive officer of Community Options, compared it to the lottery, in which players have to buy tickets to enter but don't necessarily win.

A first step is to contact a Medicaid services coordinator, who will help the individual access services. This service is available through agencies such as ACHIEVE, Catholic Charities or HCA. Caregivers also can contact their regional Developmental Disabilities Services Office for help.

"Families should learn about the scope of services available so they can work with the MSC worker, who is the coordinator, to make referrals early, so when there's an opportunity, they can take advantage of it," said ACHIEVE vice president of planning and development Amy Howard.

Families also should identify the agencies they want to work with and get involved, providers said. If the agency has a membership, join. Consider volunteering for the board or other duties, shaping policy and making sure governmental officials are aware of the needs families face.

"Families need to be advocates right now more than ever," Howard said.

Phyllis Van Hart has no problem being daughter Holly's advocate. But Holly's recent attack leaves Phyllis not knowing what to do. Holly needs constant attention, and that's difficult after Phyllis' long days as a teacher's aide for special-education students through BOCES.

Holly can feed herself, but she can't read or write.

"Holly's like a toddler," her mother said. "As soon as you're on the phone, she takes off to empty a closet or take stuff out of the kitchen. She has no sense of danger."

Historically, Holly's father has been the "entertainment committee," Phyllis said. He doesn't live with them but sees Holly almost daily and is keeping her at his home for now. Phyllis knows this is only a temporary solution. She and other family members will have to decide whether to try to get Holly into a group home — and if so, pray that there will be a spot for her.

Additional Facts

Group homes

There are 418 group homes in the Broome Developmental Disabilities Services Office's area, which includes Broome, Chenango, Delaware, Otsego, Tioga and Tompkins counties. That number includes state-operated homes and those operated by nonprofits, and reflects the ability to house 1,146 people. As of early July, there were 264 individuals in the Broome area seeking a residential placement, according to the Office for People With Developmental Disabilities.

ACHIEVE runs 13 group homes, including an apartment building, while the Handicapped Children's Association runs 10. Catholic Charities of Broome County has nine homes certified by OPWDD and two large residences certified by the state Office of Mental Health.
