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Monday, June 23, 2014

The Atlanta Journal-Constitution

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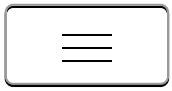

AJC INVESTIGATIONS

Mentally disabled suffer in moves from Georgia institutions

State unlikely to meet deadline from federal settlement

Posted: 12:00 a.m. Saturday, June 21, 2014

By Alan Judd - The Atlanta Journal-Constitution

At one group home for developmentally disabled adults, a caregiver punched a resident in the face again and

again. Another worker there whipped a resident with a leather belt.

At another home, a resident kept choking on food because it wasn't chopped into the small bites his doctor had ordered. He ended up in the hospital, on a ventilator.

John Alvin McGarity (left) leans down to say hello to his son, Keith, at the Southern Community Living Group home in ... Read More

At yet another facility, a man went so long without a bowel movement that he vomited blood. He died in an emergency room.

These episodes, drawn from government records, illustrate the myriad challenges facing Georgia as it transforms the way it cares for people with developmental disabilities, an investigation by The Atlanta Journal-Constitution has found.

Under an agreement monitored by a federal judge, the state promised four years ago to move all mentally disabled people from its psychiatric hospitals to homes in their communities. So far, 482 people have been deinstitutionalized.

John Alvin McGarity (right) holds his son, Keith, as he helps him stand up from his wheelchair at the Southern Community ... Read More

But, the newspaper found, many appear to be no better off – or, in some cases, even worse off –now than when they lived in the state's dangerous and dysfunctional psychiatric facilities.

Few lead meaningful lives in their new communities, according to a court-appointed consultant. They have little say over where they live, or with whom. Medical care can be sketchy. Often, group homes and adult foster homes don't hire enough caregivers or don't adequately train the ones they employ. Residents are dispersed across the state, sometimes far from family members or others who might keep watch over their treatment. If disabled people were simply warehoused in state hospitals, as their advocates often asserted, now it is as if they have been placed in small, isolated storage units that easily elude attention.

Most ominously, residents of many group homes have encountered similar patterns of mistreatment that plagued the state hospitals.

Keith McGarity looks at his hands during a visit with his father at the Southern Community Living Group home in McDonough. ... Read More

At least three-fourths of the facilities have been cited for violating standards of care or have been investigated over patient deaths or abuse and neglect reports since 2010. Officials have documented 76 reports of physical or psychological abuse, 48 of neglect, and 60 accidental injuries. In 93 other cases, group home residents allegedly assaulted one another, their caregivers or others.

Forty people died after moving into group homes. At least 30 of those deaths had not been expected.

Widespread troubles in those facilities prompted the state Department of Behavioral Health and Developmental Disabilities to suspend transfers in January - a delay, continuing indefinitely, that is likely to cause the state to miss a deadline of July 1, 2015, to complete the moves. Almost 350 disabled people remain in state hospitals, and many of them have profound medical needs that will complicate efforts to find acceptable homes.

Keith McGarity (right) holds his father's hand as he visits with him at the Southern Community Living Group home. Keith's move ... Read More

"We have to do this right, not quickly," the department's commissioner, Frank Berry, said in an interview last week. "We're not going to force people out in the community just to meet a number.

"When we accomplish this, it will be a model for the country," Berry said. "But it will take time."

The future, as Berry describes it, would fulfill a promise contained in a landmark U.S. Supreme Court case that originated in Georgia.

Frank W. Berry is commissioner of the Georgia Department of Behavioral Health and Developmental Disabilities.

Fifteen years ago today, the court ruled that states must care for disabled people in the least restrictive setting available. If people don't require segregation in institutions, the court said, they should live and

receive services in their community.

A ceremony Monday at the Carter Center in Atlanta will mark the anniversary of what is known as the Olmstead decision and will highlight successful efforts to deinstitutionalize people with disabilities.

Amid the celebration and the optimism, however, is the reality of sometimes-grim conditions in the group homes and similar facilities that have replaced institutions for many disabled people. It raises an uncomfortable, unresolved question: Were some of the people discharged from state hospitals harmed as much or more than they were helped?

- Maps: Where Georgia has moved disabled people
- Five years, 115 patients dead who might have lived
- State, Justice Department reach mental health settlement
- Report: Work remains, but Georgia's mental health overhaul significant

“If you do it right, it can be a huge upgrade for the person,” said Cynthia Wainscott, a former president of the advocacy group Mental Health America. “If you do it wrong, somebody gets rich and the person gets worse.”

Eyes on Georgia

Georgia has a long, dark history of mistreating people with disabilities.

- Asylum's dark past relived as cycle ends
- Olmstead settlement

The state first opened what it described, in the blunter language of the day, as an insane asylum in Milledgeville in 1842. Deep into the 20th century, people with developmental disorders - Down syndrome, autism, and traumatic brain injuries, among others - were sent to Milledgeville, often for what became a life sentence. They lived in infirmary-style dormitories, their beds lined up just a few feet apart. Their medical care often was poor, and some were subjected to unauthorized pharmaceutical experiments and questionable treatments, such as lobotomies.

Among those recently discharged from the state hospitals, many were first admitted as children and lived in state institutions for 40, 50, even 60 years. Georgia Regional Hospital/Atlanta still houses a 95-year-old woman who has been institutionalized since 1941 – 73 years.

The state vowed to overhaul its mental health and disabilities system after the Journal-Constitution published articles in 2007 detailing abuse, neglect and more than 100 preventable deaths in state hospitals. The U.S. Department of Justice later alleged that hospital conditions violated patients’ civil rights and threatened to sue the state. A 2010 settlement called for massive state investment in community treatment programs and for the discharge of all people with developmental disabilities. The Justice Department has used the Georgia settlement as a template in addressing similar problems in other states.

“The whole country is looking at us,” Berry said recently. “We get reminded of that by the Department of Justice every week.”

The Justice Department says Georgia has improved its mental health services. But, as government lawyers wrote late last year, the state’s developmental disabilities system “now stands on (a) razor’s edge” between a new approach to treatment and a failure to provide acceptable care.

The Journal-Constitution’s examination confirms that assessment.

The newspaper reviewed more than 5,000 pages of reports detailing state inspections and investigations of the facilities that now house people with developmental disabilities. The documents depict a continual stream of indignities and injuries, ranging from residents denied their own toothbrushes to caregivers delivering brutal beatings.

At several homes, according to inspection reports, caregivers failed to make sure residents went to routine medical appointments. In addition, the reports show, many homes have not maintained accurate medication records or ensured that physicians actually prescribed the drugs given to residents. An inspection of one home found 179 medicine bottles belonging to 10 residents – all, somehow, with the same prescription number. Officials couldn’t figure out whether all the residents were supposed to actually get the medicines they were taking.

Many homes seem unprepared to manage difficult residents.

A resident of a group home in Lithonia was serving a probated sentence for assaulting a former girlfriend. His treatment plan required one-on-one supervision at all times. But he “roamed the community,” a state report said, leaving the group home at will. Every evening, the home’s staff had to track him down to administer his medications. Still, it wasn’t until the police arrested the man for allegedly beating another girlfriend that state officials established just how frequently he walked away from the group home: 25 times in five weeks.

In other homes, residents’ unruly behavior has led to assaults by housemates and abuse by caregivers.

Last year at a home in Columbus, a resident aggressively grabbed a staff member by her collar. Another worker intervened, bending back one of the resident’s fingers until he flinched in pain. Later, she squeezed her hands around his throat and threatened to beat him. After the incident was reported to state officials, the group home suspended the worker.

Few details are available on the 40 cases in which residents died. State officials heavily redacted reports on those cases, removing the residents’ names as well as passages that explained why they died and whether their caregivers bore any responsibility.

Many of the deaths appeared to be from natural causes; several people died in hospice care after extended illnesses. But in most of the death cases, exactly what happened will never be known.

When a person dies in a state hospital, the law requires an autopsy to determine the cause and circumstances of the death. But in at least 27 of the 40 deaths in community-based facilities, records show, no autopsy was performed.

“Father ... did not request one,” a report explained in one case. “Family decision,” another report said.

In 10 cases, reports don’t indicate whether an autopsy was performed. Only three of the 40 reports say the examination was ordered.

Officials say less-than-ideal conditions in group homes may have resulted in part from the urgency with which they were moving people out of state hospitals. They struggled to meet quotas set by the settlement agreement, including an arbitrary requirement that 150 hospital patients be transferred every 12 months.

“We were trying to transition people at a pace, volume and complexity beyond what we could handle,” said Judy Fitzgerald, a deputy commissioner of the state behavioral health agency. “We will adjust the pace in a way we can assure the health and safety of individuals.”

Berry, the behavioral health commissioner, said the agency requires service providers to report practically any harm to a resident, from a minor cut treated in an emergency room to a death.

What the reports don’t show, Berry said, is that many residents are thriving in the first real homes they’ve had in decades.

After 48 years, a home

Keith McGarity lived in state institutions through the Cold War and rock ‘n’ roll, Vietnam and man’s voyage to the moon, Watergate and disco, the Internet and 9/11 – 48 years, beginning when he was just 7 years old.

Keith, now 58, was born with Down syndrome. His parents tried to keep him at home as long as possible, but he became too difficult to handle. His mother, Catherine, was “beaten down – physically and, you might say, mentally,” Keith’s father, John Alvin McGarity, recalled recently.

So in August 1963, Keith entered Gracewood, a state hospital near Augusta. It would be the first of three institutions where he would live until 2011.

The institutions took good care of Keith, his father said. When McGarity learned his son would be transferred to a group home, he was wary.

Keith is essentially non-verbal; he has never said more than “mama,” “dada” and “baby, baby, baby.” He could never advocate for his own needs. In the state institutions, McGarity said, Keith had easy access to doctors, nurses, therapists, dieticians and other professionals.

“That’s something you don’t like to give up,” McGarity said.

At Keith’s new group home in McDonough, “they take care of all his physical needs,” McGarity said. “If he gets sick, he goes to the doctor. I really don’t see how it could be better.”

Best of all, McGarity said, Keith now lives just six miles from his home in Hampton. McGarity, 84 and widowed, visits at least once a week.

“We like to pat hands and play and listen to music,” McGarity said. Keith is partial to Christmas songs and marches by John Philip Sousa.

“My wife always said things happen for the best,” McGarity said. “I couldn’t be happier for him being with somebody.”

‘You have to move’

No one expected moving disabled people from institution to community to be easy.

“You’ve been living in an institution for 50 years, and that’s all you’ve ever known,” said Eric Jacobson, executive director of the Georgia Council on Developmental Disabilities. “And now you have to move.”

The transition may be especially difficult for those remaining in state hospitals. Many require intense medical treatment, such as respirators or feeding tubes, and their conditions often are described as fragile.

“These are the hardest folks to move out,” Jacobson said.

Consider the 95-year-old woman who has lived in state institutions since 1941. Or the 87-year-old man who lives down the hall from her at Georgia Regional. Finding homes that can adequately care for them may seem impossible, Berry said, but he plans to try.

While visiting the 95-year-old recently, Berry said, he was struck by how alert she seemed. She is tiny, he said, and always wears a hat, even though she stays in bed most of the time. She can’t speak, and her vision is failing. But Berry said she clearly enjoys hearing people’s voices and responds warmly to a touch on her hand.

He has reviewed her voluminous hospital records, accumulated over the decades, trying to understand why she was institutionalized so long, and why so many others were, too.

“At what point,” he said, “could we maybe have found a home in the community for her?”

Landmark ruling

June 22 is the 15th anniversary of a U.S. Supreme Court ruling in a Georgia case about the rights of disabled people. The court rejected forced institutionalization of people with mental disabilities who are able to live in community settings. But Georgia is still struggling to comply with the law. Among the key developments:

7/26/1990: Americans with Disabilities Act of 1990 signed into law.

In this Section

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6/4/2008: In the first of a series of blistering reports, the Justice Department details "critically deficient" conditions at Georgia Regional Hospital/Atlanta. It gives the state 13 pages of necessary corrective measures.

6/12/2008: Perdue recommends cutting $8.4 million from mental health services for children to cover deficits in other social services programs.

7/1/2008: Perdue announces the state had reached an agreement to help move mentally ill and developmentally disabled Georgians out of the state's psychiatric hospitals and into community settings.

1/15/2009: Georgia signs agreement with the Justice Department to take 345 steps within a year to improve the state's seven psychiatric hospitals.

9/30/2009: After mental health advocates complain the agreement is inadequate, U.S. District Judge Charles

Pannell withholds approval of the proposed settlement. State and federal negotiators resume talks.

11/1/2009: Central State Hospital in Milledgeville, the state's first psychiatric hospital, stops accepting new patients following a federal inspection that found inadequate treatment, dangerous conditions and violence among patients.

1/28/2010: In a 700-page complaint, the Justice Department contends the state has moved too slowly to overhaul mental health services and asks a judge to appoint an independent monitor to direct the shift in state psychiatric hospitals.

6/30/2010: After an unsuccessful round of negotiations with the state, federal authorities ask Judge Pannell to force Georgia to make substantial improvements in its psychiatric hospitals and its community-based treatment services.

10/19/2010: To avoid a federal lawsuit and a possible takeover of its mental health system, Georgia signs a settlement agreement that calls for $77 million in new spending.

7/1/2011: Georgia's state hospitals stop admitting people with developmental disabilities.

8/28/2012: Georgia asks a federal judge to delay for one year a scheduled review by a court-appointed monitor.

5/17/2013: Concerns about quality of care at group homes and other community settings prompt the Georgia commissioner of behavioral health to impose a 45-day moratorium on moving developmentally disabled people out of state hospitals.

12/31/2013: State closes Central State Hospital nursing home that housed individuals with developmental disabilities and mental health issues.

1/7/2014: Georgia again suspends transfers of developmentally disabled people out of state hospitals.

6/22/2014: On the 15th anniversary of the Olmstead decision, almost 350 people with developmental disabilities remain in state hospitals.

7/1/2014: Deadline under the 2010 agreement for Georgia to establish a dozen crisis respite homes for people with with developmental disabilities and their families. The state also is to have resources in place for individuals to remain in their community setting.

7/1/2015: Georgia is to have transferred all state hospital patients with developmental disabilities to community settings by this date. It also is to have the capacity to provide supported housing to any of the 9,000 individuals with serious and persistent mental illness served under the agreement who need such support; and housing supports to 2,000 individuals who are deemed ineligible for any other benefits. The

state also has to provide supported employment to 550 individuals.

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Mentally disabled suffer in moves from Georgia institutions

Ethics commission ready to move forward, but obstacles remain

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John53 Report

Anybody with common sense, compassion and recall of history could have seen this coming. Northwest Georgia Regional Hospital sits empty when it could solve much of the problem by simply moving patients in there and providing them with optimum treatment.

11:28 p.m. Jun. 21, 2014

fairness23 Report

Olmstead is about CHOICE, not forced deinstitutionalization!

10:21 a.m. Jun. 22, 2014

fairness23 Report

Excellent, detailed article. Thank you so much for the exposure of this travesty. My daughter resides in a state run facility for developmentally disabled in Georgia. She has received excellent nursing and medical care. From physical therapy, occupational therapy to chapel services, the staff have been our family and loved our daughter as their own. She is being moved out next week. My daughter's roommate of nine years was transitioned to the "community" and died within ten months. The mother requested an autopsy and was denied??? The child was only 12 years old.

10:40 a.m. Jun. 22, 2014

Harlequin

Report

Some group homes strive to do a really good job and others are "three hots and a cot." Some group homes are not staffed during the weekdays and staff are often paid so poorly they have to work second jobs. (Low pay and benefits are not conducive to attracting and retaining quality personnel whose jobs are often difficult. At one time in Georgia, one new group home might be added in a calendar year while at the same time, state hospitals were rushing to discharge patients with developmental disabilities. Group homes are supposed to be as home-like as possible with no more than six residents. A group home being established in a residential neighborhood has a way of bringing the NIMBYS (Not In My Back Yard) to the next homeowner's association meeting. More group homes are and will be, needed, as many people with developmental disabilities will outlive their parents and the state hospital is no longer an option for those with mild to moderate impairments who cannot live independently. (Some higher functioning people can live in supervised apartments or independently.) People with Developmental Disabilities and/or Mental Illness are the state's most vulnerable population and the State of Georgia should not be allowed to duck their responsibility concerning them. Pretending it isn't there will not make it go away!

9:13 p.m. Jun. 22, 2014

Comment(s) 1-4 of 4