

Texas and Arkansas avoid Georgia example

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SPECIAL



Christen Shermaine Hope Gordon is photographed in 2002. Christen was one of 500 patients to die living in community care in 2013.

Advocates for the developmentally disabled in Texas and Arkansas looked at Georgia's experience with patients in community care and vowed not to let it happen in their state.

Earlier this year, *The Augusta Chronicle* published the results of a year-long investigation that found nearly 1,000 people died over two years while in community care homes under the auspices of the Georgia Department of Behavioral Health and Developmental Disabilities. Of those deaths in 2013 and 2014, 223 were considered "unexpected deaths.

As the deaths mounted in the first part of 2013, the state halted a mass deinstitutionalization of patients from state institutions that it agreed to under a 2010 settlement with the U.S. Department of Justice. State officials have said they recognized a need for greater training and preparation of community providers to receive those patients, many of whom are medically fragile and require higher levels of care and attention. But Independent Reviewer Elizabeth Jones, in her report on the state's progress over the last five years, found that the state's own report "described in unsettling detail the lack of trained staff currently responsible for individuals with a developmental disability" in 27 of those agencies and "point to the urgency to recruit and retain competent providers."

For its part, the department did not respond directly to *The Chronicle* series except to request that "interim" be removed from an official's title. About four months later, however, the department published its first Annual Mortality Report on disabled people being cared for in the community during that same time period. The department found those patients accounted for 131 deaths out of all of the 11,544 served, a rate of 11.3 deaths per 1,000 patients, and 128 deaths in 2014 out of roughly the same number of patients for a death rate of 11.1 per 1,000 patients.

However, those rates are only for adults receiving community care through two specific Medicaid waiver programs and does not include 15 children who died during that same time period, including 12-year-old Christen Gordon, whose death in 2013 inspired the newspaper's investigation. The state's mortality rate also does not include 45 other patients who died but were not on the same waiver programs because the state felt including them would "produce upwardly biased mortality rates," according to its report. The department pledged to use the analyses of

deaths to help shape future training and is “committed to its continued review of all available data to know what is working and what needs improvement.”

BUT THE ARTICLES caught the eye of advocates in other states who are trying to keep their loved ones in state institutions from encountering a similar fate. In Texas, the state Senate had passed a bill that would have closed the Austin State Supported Living Center and would have established a commission that could have then identified the next six to go, said Liz Belile, an advocate in Austin whose sister has been in a state school outside Houston for over 40 years. A core group of family members then began to lobby the state House of Representatives, including making sure they saw *The Chronicle’s* stories and numbers, she said.

“I think for a lot of people it was a turning point,” Belile said. “We made sure that every representative in the legislature saw that data. We were tweeting it, getting it out there. I know that we referenced it repeatedly. I sent it to family members and people who were working to keep their living centers open.”

The group also collected a petition of 5,000 signatures opposing the move, rallied the media, and were able to convince the local delegation to oppose it. Rep. Susan King, R-Abilene, then proposed a series of amendments that took out the part of the Senate bill that would have closed the Austin center and set up the commission to propose the other closures. But even with a reprieve, Belile said advocates are still being vigilant.

“There’s no question they’re going to try to figure out a way to shut the living centers down,” she said.

Arkansas parents and guardians fought and won a court case against the Justice Department in 2011 when it sought to move patients out of the Conway Human Development Center, one of the few cases where the federal agency has lost on this issue. But now advocates fear state officials might be readying to try the same thing under the guise of managed care and health reform.

ARKANSAS GOV. ASA Hutchinson appointed a Legislative Task Force on Healthcare Reform and an Advisory Council on Medicaid Reform. When a consultant to the task force recommended that the five Human Development Centers be closed and the clients there be moved to community care, the parents and guardians swung into action again. In a meeting with Hutchinson, parent Rita Hoover handed him *The Chronicle’s* series and when she cited the Georgia statistics to him and his staff “they were very surprised,” she said.

Last week in a presentation to the task force, Hutchinson was specifically asked about the future of the centers, Hoover said.

“The governor said he supported the Human Development Center system and he did believe that our state needed to continue that system, that there is a need for longterm care facilities in our state,” she said. “We feel like we have a victory on a small battle. We don’t think the war is anywhere near over.”

Fighting for the centers is a constant struggle, said Jan Fortney, secretary for the Families & Friends of Care Facility Residents of Arkansas. Her daughter, Kim, has been in the Conway center for over 20 years with Hoover’s son, Tim. They fight to show the centers are efficient and

that “our fragile loved ones are not going to be cared for any cheaper in the community,” she said.

They cite the Georgia stories to show what can happen in the community to those patients, Fortney said.

“People don’t understand that is absolutely the truth,” she said.

And they don’t understand how these patients, who often need around the clock care like her daughter, view the centers themselves. Kim comes home with them for a night or two “and then she’s ready to go home,” Fortney said.

“That’s her home, absolutely. She’s just got the best of both worlds. I am so grateful for that place, I’m grateful for the staff. I just can’t tell them enough how much we appreciate them. And you know, they’re her family, too. They love her.”