

Legislature considers bill to regulate Disability Rights Arkansas

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About 75 years ago, people with severe intellectual or emotional disabilities in Arkansas were relegated to one state facility in downtown Little Rock

In the late 1800s, it was called the Arkansas Lunatic Asylum. About 20 years later, the name changed to the Arkansas State Hospital for Nervous Diseases. And in 1933, the state settled on its current title: the Arkansas State Hospital.

Now, families have a few more options. There are five Human Development Centers scattered around Arkansas. These are long term care facilities where residents eat, work, sleep and live among people with similar challenges or diagnoses.

Katrina Robertson's son lives at the HDC in Booneville. His name is Noah, and from his adoption at age nine, he needed full-time care.

"He comes from extreme abuse and neglect and has some pretty significant behavior issues," she said. "He is dual diagnosed with both mental health issues and the intellectual disability component as well."

When negotiating Noah's care, Robertson was stuck navigating a thicket of bureaucracy. She said the stress caused her to lose her hair.

Noah's a runner. He's run away from home and spent time in a homeless shelter. At one point, Robertson put him in a facility in Utah. That worked for a year. Then, she put Noah in a cottage near her house with staff.

She had trouble with the full-time staff, who were often fresh out of high school and making minimum wage.

"Trying to staff him was literally a full-time job," she said. "You never knew if they were going to show up, if they were going to leave, if they were going to get him involved in whatever drama they had going on. I had one bring him to a drug deal. I had one steal a car. It was a nightmare."

She says, at one point, Noah spent 44 days in an emergency room sedated, sleeping on the floor.

Robertson decided to try placing Noah at a Human Development Center. She heard the Booneville HDC was adding beds for people with more advanced behavioral challenges. This could be her chance.

So, while Noah was still in the hospital, Robertson made a phone call to Disability Rights Arkansas (DRA), a nonprofit specializing in services and oversight for the state's disabled population. DRA gets money from the federal government, not the state.

Robertson told DRA that she wanted to put Noah in the Booneville HDC. She says they weren't receptive. They tried to talk her out of it.

"And I told this to the DRA attorney and he said 'but he deserves to live with dignity within the community.' So, you can see how as a parent that would make me feel, you know, how awful it was that I would be considering that as an option for my son."

Robertson said to the lawyer before she concluded the call "you will hear from me again."

This call is a relevant marker in the history of the nonprofit. Robertson talked about it in her book, and she talked about it in front of the state legislature. It seems to be when a lot of the tension between DRA and families with loved ones in HDCs started.

Robertson says DRA doesn't like long-term care facilities. They prefer community placement, which isn't feasible for everyone. DRA says they are not a placement organization, but there could be abuse at these facilities — abuse they want investigated.

Robertson's says her experience with her son at Booneville has been wonderful. She recently attended the HDC talent show where she watched Noah perform the Christian hymn "How Great is Our God."

"He was in the front giving standing ovations to his friends during their little performances," she said. "And he got up to do his little number. I finally kind of had this realization."

That realization: sometimes communities try to accommodate disabled people by putting them next to the non-disabled, but this inclusion can be a form of isolation.

Noah was less alone when he was at Booneville, a facility with people like himself.

Disability Rights Arkansas does not run Booneville, but they have the authority to

each HDC uses physical restraints, and how often they chemically sedate people. They look into allegations of abuse.

They are the watchman, watching the watchman.

Meanwhile, Robertson is part of a parent's group that finds fault with DRA. There is a general anxiety in the group that DRA may try to shut down places like Booneville. The DRA, she supposes, is aiming at a dead target; they would be more useful investigating abuse in the community, not these facilities so many families rely on.

But, DRA couldn't shut down Booneville if they wanted to. The group doesn't have the power to close institutions.

Whether or not they want to shut them down is a fuzzier question. [In a 2015 report](#), DRA recommended the facility close. But there hasn't been any meaningful movement to make that happen; in fact, the state has increased its funding.

"It's been boilerplate in the budget bill that says no state Human Development Center will close without approval from the legislature," said Tom Masseau, executive director of Disability Rights Arkansas. "All we can do is investigate, talk to the state about the work and provide an idea of what we're seeing."

The reports DRA has written on facilities like Booneville read the way a Hieronymus Bosch painting feels to look at. They describe piles of trash in abandoned and rotting rooms, mosquitoes in an unused pool, mold everywhere and buildings which don't accommodate wheelchairs.

[Around 2023, an HDC patient came to the hospital bony and emaciated.](#) The DRA investigation said staff wasn't allowing him to finish meals.

In another incident, an HDC patient presented to the ER covered in burns after he had been scrubbed down by a staff member. At one facility, a patient with a broken arm waited two hours before being taken to the hospital.

And it's true that a resident at Booneville died while being restrained. Resident David Cains was said to have the IQ of a four-year-old and an illness that caused him to aspirate his food. [In 2020, minutes after a meal, he aspirated and choked to death.](#)

"[Restraints] should be if they are an immediate threat to themselves or to someone else," said Regan Stanford, an attorney who was a part of the external investigation into the death at Booneville. "We don't always see that, and I think it's questionable in this case whether that was occurring."

The Arkansas Department of Human Services, which oversees Human Development Centers, gave a statement to Little Rock Public Radio.

"Safety is always a top priority, and any allegations of abuse or neglect are swiftly and robustly investigated." This is true in the sense that Booneville did their own internal investigation into the death, but that investigation was led by staff at the center.

DRA's investigation took longer and was detached from any close relationship to the institution. Their findings did not reflect well on Booneville, and the research they collected was used in a lawsuit. David Cains' family sued the State of Arkansas and won. His sister was recently given \$400,000 by the state.

The DRA describes these places as institutional black boxes. Stanford says it's not unusual for people to report to her that a loved one turned up with a strange or unexplained injury.

In her mind, there shouldn't be this much mystery. Human Development Centers could easily install cameras. But despite years of DRA pleading, there are very few cameras in Arkansas HDCs.

Katrina Robertson tells a different story. She says Noah doesn't have mystery injuries because the facility always tells her when he gets hurt.

"Like I got an email yesterday," she said. "He fell and I think bumped his knee. Didn't even break any skin. If he gets any mark on him whatsoever I am notified. If he's having to be restrained they both call and email."

Another parent who spoke to Little Rock Public Radio said the same thing: the facilities are communicative, especially about restraints and injuries.

[And each HDC releases numbers to the DRA showing how often they use restraints.](#) Booneville's numbers are higher than other HDCs, so they are either better at

Still, the picture painted by these HDC investigations chronicle a scandal foretold.

For one, HDCs are understaffed. Workers aren't paid very much. A recent job posting offered a starting annual salary of just over \$30,000. Sometimes, you only need a high school diploma to apply.

"There does seem to be, more than I like to believe there is in the world, maybe some active cruelty by some individuals," Stanford said. "But a lot of it is I think they are not trained."

Stanford says residents do a lot of "sitting around," because there isn't much to do as a resident in an HDC. There isn't enough staff to provide therapeutic services, and there's not much stimulation. Residents are allowed to work, sometimes making rugs for a local store, but the facility has a waiver to pay them less than minimum wage.

DRA has opposed these waivers, going so far as to speak against them at public events.

Robertson said Noah doesn't need a minimum wage income; his necessities are covered, and if he was able to get competitive employment he wouldn't live at Booneville.

"It has nothing to do with a paycheck, that's irrelevant," she said. "All my son knows is, he calls it his pocket money."

Stanford said she doesn't want to close these facilities down. These patients have the right to be safe, she says, so she wants patients and their guardians to have a choice.

But what does a choice mean to someone who is intellectually disabled?

"Noah is very verbal," Robertson said. "If you went to him and said 'hey do you want to live in your own apartment and do you want to have a job that pays more,' he is going to say 'yeah I want my own apartment.' He'll say he wants to drive a car. That's not in his best interest."

Right now, [a bill](#) is moving through the legislative gauntlet to regulate Disability Rights Arkansas. Rep. Jack Ladyman, R-Jonesboro, put forward a bill giving a legislative

committee oversight over the board. Ladyman's own son is in an HDC, and he is supported by the parent's groups who believe DRA wants these facilities closed.

"They have no oversight at the state level," he said to committee members. "They submit reports to a federal organization and other organizations that fund them."

The bill would subject Disability Rights Arkansas to the Freedom of Information Act, and they also would have to submit biannual reports to a legislative committee. That committee is run by a state government overseeing Human Development Centers. HDC's are also overseen by DRA.

It's a confusing ouroboros of the watchman, watching the watchman, themselves watching the watchman.

DRA leader Tom Masseau says this bill is untenable. For him, the point is they are independent. How can they do these investigations if they have to worry about oversight from the government?

"Specifying one particular nonprofit in the entire state, and putting it into the law that we come before a committee," he said. "No other nonprofit in the state is subject to this."

It's unclear how the bill would affect DRA. It's also unclear if this bill could hold up in court, as their money may be protected from state oversight. But Masseau says it could harm the group's functions and operations, forcing them to become something else.

Robertson has called statements from Disability Rights Arkansas "misinformation." She says the bill just creates more oversight and requires DRA to answer more questions.

In their conversations with Little Rock Public Radio, DRA representatives expressed a kind of muted confusion. These family groups are making them seem like the enemy, when in their minds they are all standing on the same shoreline, facing the same goal post.

Both groups want the best for disabled Arkansans. What that means though, for a complex population of people with unique needs, is harder to know.

In a statement, the Arkansas Department of Human Services said "Staff work tirelessly

environment where residents with developmental and intellectual disabilities can thrive.”

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