

**GRAY MATTERS**

# My disabled sister loves her living facility. Texas could take it away.

**Liz Belile, for the Houston Chronicle**

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A Sunset Commission recommended in 2015 that the State Supported Living Center in Austin be closed. In this photo: The writer Liz Belile with her sister, Shanna, who lives in the Austin SSLC.

Photo: Liz Belile

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breath, and then it'd be over.

Only to repeat itself, again and again.

My mother reported the odd behavior to family members and to doctors to no avail. *There's something wrong with the baby.* After all, Shanna was the first born of twins, who came early and needed to recover in an incubator. (This was the late '60s.) Epilepsy ran in the family. She did not develop in sync with her twin brother, who was walking while she was just rolling over.

Finally, after at least one grand mal seizure and hospitalization, the doctors were able to name the issue: Lennox Gastaut Syndrome. It is an uncommon form of childhood epilepsy that usually comes with intellectual disability. Unfortunately, it does not respond well to

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frightening; we witnessed many.

By the time Shanna was elementary-school age, after years of occupational and physical therapy at home, after multiple, devastating injuries from falling in seizure and behavioral issues that my parents exhausted themselves trying to manage, the pediatric neurologists recommended that they place my sister at the new, state-of-the-art school for the "retarded" outside of Houston, in Richmond.

It was a tough but inevitable choice; my sister had been bullied by other children all her life and by her Special Ed teacher in our public school. (Who lost her job because of it.) Shanna had been found by

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neighborhood, dropped off in the wrong place by the substitute bus driver.

My parents had had enough.

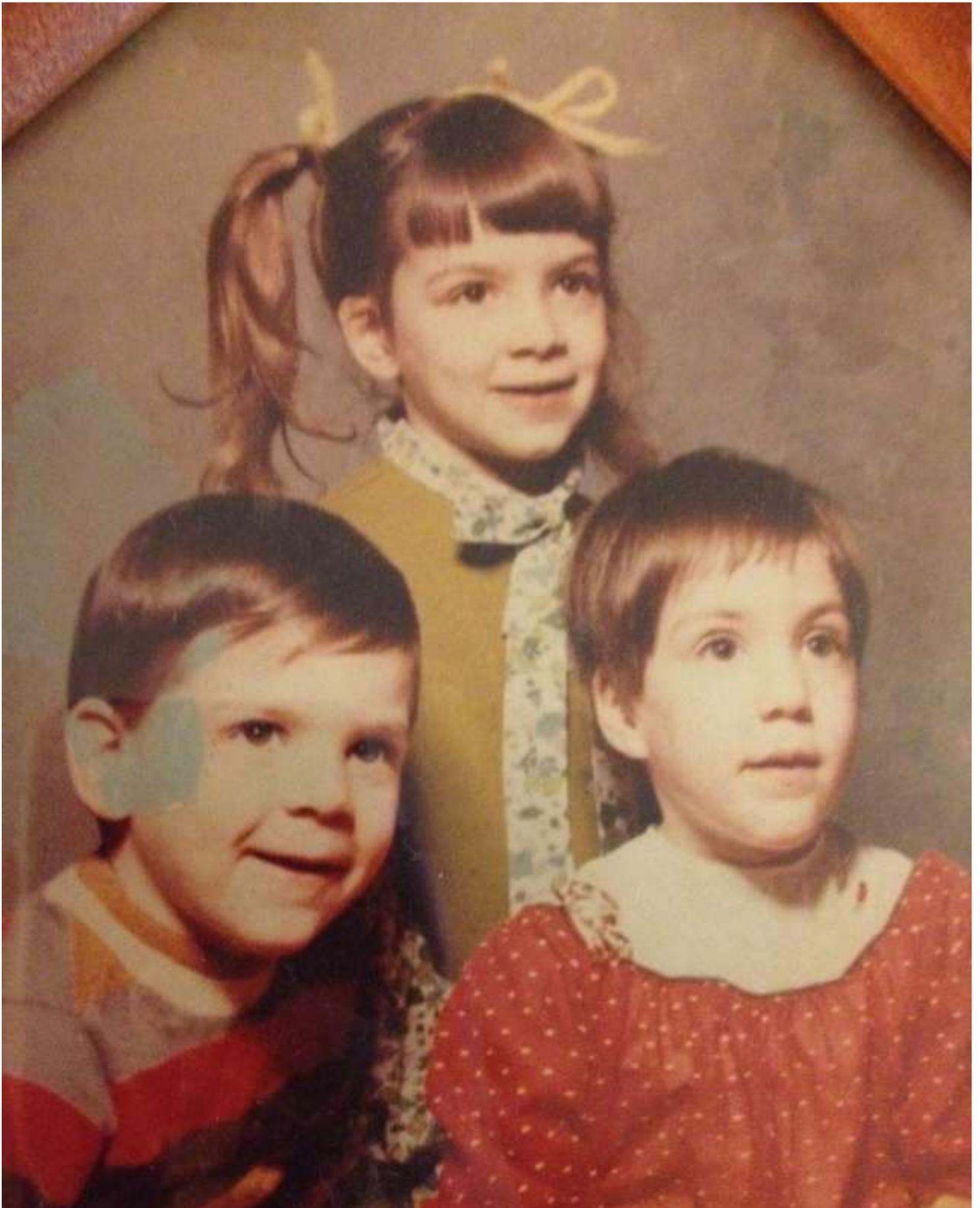
I will never forget the tears streaming from behind my mother's big, round Gloria Steinem sunglasses as she drove us back, the Richmond State School's lovely rolling hills disappearing in the rearview mirror, having left her precious child there to live.

Shanna was nine years old, the same age as my son now. I can't imagine the heartache, though I know the ferocity of doing the right thing for your child. It took years of visits for Mom to not leave sobbing her heart out. My brother and I cried too, but like our parents, we wanted the best for our sister. We knew that at Richmond, Shanna would have activities. Medical staff would be at the ready when she had another one of her horrifying seizures. She would have peers. She would have friends. Oh, that was what finally sold me on the idea. That made sense.

What we couldn't understand, though, was suddenly being shunned by families who had disabled children living at home. I had friends with siblings who had severe cerebral palsy, who had traumatic brain injury, mild cognitive or intellectual disability or even "only" a physical disability. Growing up, I never knew anyone who'd had a seriously complex disabled sibling who required care in a medical setting. The effects of such a thing on a family can be isolating and traumatic.

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Belile with her twin siblings. Shanna, on the lower right, would be diagnosed with Lennox Gastaut Syndrome.

Photo: Liz Belile

Fast-forward 42 years.

I have unwittingly become the poster child for the "Sandwich Generation," as I am the mother of a young child who is both gifted and has learning differences, and I have an elderly parent who is physically disabled and resides in an Assisted Living community. I also became Shanna's legal guardian in 2014. With our dad gone and our mom's health in decline, it just made sense.

**UP UNTIL this month, Shanna** lived and thrived at the Richmond State School, now known as a State Supported Living Center, or SSLC. After years of fighting to keep our SSLCs open, and working with fellow guardians and advocates within the Department of Aging and Disability Services, I had her transferred to the SSLC in Austin, where we all live now.

SSLCs – Texas has 13, in all – went under scrutiny by a Sunset Commission, as part of the investigation of our Health and Human Services agency, specifically DADS, or Department of Aging and Disability Services. They have all been under settlement by the Department of Justice since about 2010 to improve them. A Sunset Commission is a serious thing, seeking to streamline, fix or even abolish entire agencies.

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In 2015, the commission recommended that the state immediately close the Austin SSLC and that our lawmakers create a "restructuring committee" to examine the 12 others in Texas to determine which would be closed next. Word on the street was that anyone living in an SSLC who did not have a legal guardian would soon be needing one.

I was told that my sister should be living "in the community," in a group home, with no more than three other people with disabilities, with (usually) one caregiver to supervise them at home and, in her case, with one "awake staff" caregiver who would be on alert at night while the residents slept. I have to admit I was intrigued by the idea.

But I was also concerned. At Richmond, she lived in a dorm with about 20 other women with similar disabilities, with a much smaller staff ratio of about 2:1, with multiple caregivers in the building circulating at all times. There are security cameras in the common areas. Plus 24/7 medical professionals on site. And dental care. Physical therapy, occupational therapy, equestrian therapy, music therapy, swimming therapy, even medical specialists who regularly visit. All on site. My sister participated in the equestrian therapy program on campus, which also serves people of all abilities from the community.

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Shanna and her mother, Dorothy, at the Richmond SSLC with the equestrian center that Shanna enjoyed in the background.

Photo: Liz Belile

In Austin, she has almost all those same therapies with the added benefit of having her family near. I can drop my son off at school and swing by to check in with her any time I want. There is no greater safety for her, or for any vulnerable person, than having a loving family's support and protection. I am already friends with her primary medical provider, who calls and texts me with every little thing Shanna-related. I've sat in legislators' offices and testified on behalf of keeping our living centers open. I'm Facebook friends with her

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am close to several women whose sisters live in the same home as Shanna. We all visit often, and we check on our sisters for one another.

Shanna spends her mornings and some afternoons in a "sheltered workshop," where she earns some spending money through a special work program run on campus, which she loves. She uses a wheelchair and requires two people to assist her daily activities and movements. She has a special ground diet to help avoid aspiration, which happens so fast and so often with people with disabilities it's shocking.

During this time of transitioning her to her new home, a caregiver monitors her sleep by checking her every 15 minutes to make sure she is secure in bed, due to her seizure activity. When I visit, the other ladies in her new home swarm me and let me know that Shanna is their beloved friend. It is deeply moving. She is happier than I have ever seen her.

**IT MAKES my blood run** cold to think that it could all be gone in the blink of an eye. The Austin SSLC is in the most prime real estate in the city. It's five minutes from Seton Medical Center, in central Austin, across from the military base.

Most of the state-owned property in central Austin has been sold for mixed-use development; we have a serious affordable housing problem here and a serious influx of new residents. But the SSLC has been here for 100 years. It is woven into the fabric of the surrounding

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and therapists and medical professionals and social workers who have worked here. State jobs are a golden ticket for an Austin creative type.

But the SSLC property is slowly being devoured, two acres of it already auctioned off to a developer who built luxury condos right up against a set of cottages the state vacated in 2015. I fear that a "restructuring committee" will just finish the dirty work started by General Land Office Commissioner Jerry Patterson just a few years ago and put the SSLC on the chopping block.

Still, to go from 24/7 care and support to very limited, unskilled care and support, all in the name of "more independent" living seemed questionable, but I was told that people with very high needs thrived in the community as well, so I was willing to explore Shanna's options.

I visited every group home in the Austin area that could accommodate her wheelchair – not many group homes actually accommodate wheelchairs – and the day facilities where she would be required to spend eight hours a day, every day, with occasional "field trips" into the community. And what I saw terrified me: Poor living conditions, overcrowded and unstructured (and as it turns out, unregulated) adult "day habilitation" sites, minimum wage caregivers being expected to provide the same level of care for her as the highly trained caregivers at Richmond, unresponsive management and unsupervised exposure to people I had no way of vetting.

My sister could never communicate to us if she were abused or neglected. And since nearly 90 percent of women with intellectual

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As a parent, I would never leave my child in a daycare or school setting that I could not vet in some way. Why would I be willing to leave my sister in the care of a company, whose motive for existing is, after all, the bottom line, with massive turnover rates (granted, the same problem exists at our SSLCs, but my sister had had some of the same caregivers and managers for decades) and profit? Such a company would be unlikely to hire a medical professional, for example, at \$25 to \$30 an hour and keep her on site for just four people in a group home. Especially if they are managing 50 group homes, all spread out, in the suburbs of Austin.

Meanwhile, in a larger facility for, say, 200 people, we can afford to keep 24/7 medical professionals on site and on call. And with redundant staff, the likelihood of reporting abuse increases tenfold. Community advocates argue that if disabled people are out and about in the city, concerned neighbors and citizens will help protect them by reporting abuse. But for people with intellectual disabilities, as with victims of domestic violence, this is an unreliable system at best, deadly at worst.

**THROUGHOUT SHANNA'S life, the seizures** have changed in nature, but never stopped coming. A recent EEG revealed that she has seizures even in her sleep. And yet she enjoys her life. But with continuous seizure activity, she is truly a girl, interrupted. Her neurologist confirmed it for me: Shanna cannot live in a group home setting; she must reside in an SSLC or similarly equipped ICF. I am not willing to let

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So sue me.

In my crash course on deinstitutionalization, I learned that though some people who had been transitioned out of state-run facilities, sometimes called ICFs or Intermediate Care Facilities, fared quite well in a group home or community setting, in the state of Georgia there had been more than 1,000 "unexpected deaths" in the community over the course of two years. Now the families of those who transitioned out of institutions (were forced out by closure, more like it) are suing the group home provider. And it's happening all over the country, as we speak. I desperately want Texas to avoid this fatal mistake.

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The SSLC has been in Austin for 100 years. It is woven into the fabric of the surrounding neighborhoods. In this photo: Austin SSLC resident Gayla Paulette Regian with her older sister Linda Johnson in Austin.

We have congregate care in assisted living communities for our aging adults – why not the same for our complex disabled? An assisted living community is pennies to the dollar, far more affordable to the operator than would be overseeing the care of hundreds of similarly high needs people in dozens of homes spread out across the region.

The cost effectiveness of 24/7 supervision, oversight and medical personnel or highly trained caregivers in a setting for 200 people in one facility vs providing similar care to 200 people in 50+ spread out suburban houses is incomparable. Group home providers cannot afford to keep a nurse or doctor on site 24/7.

What's more, as all people age, their needs become more complex. Elderly people who are disabled need a much more highly trained staff. In an "institution," with all of its "institutional memory" and structure, it becomes affordable and easy to educate large numbers of caregivers who need that extra training.

Congregate living requires annual inspections; having one facility to inspect rather than 100 group homes is more cost effective. It takes years for the state to inspect every group home just once a year. For an already overtaxed Health and Human Services agency, do they want to add more group homes to inspect?

The complex disabled make up a small percentage of the vast nonuniform and wildly varied disabled population. It seems incredibly

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like "normal" people. I'm sure my son would love to eat candy all day like "normal" kids, but what he really needs is vegetables. And structure. And guidance. And support.

With all the budget cuts from last legislative session, the scandals surrounding Special Education in Texas and the failing foster care system, it has begun to feel incredibly bleak for those of us out here who are trying to make ends meet and still afford the special therapies for our kids, as we watch our parents' life savings drain away, all going toward their senior housing and healthcare.

The good news is that I love my family, and I love my life. The bad news is that Texas ranks near the very bottom in terms of providing Special Education, services for the elderly and for the intellectually and developmentally disabled. Those of us firmly ensconced in one of the tiers of the middle class (or lower) who have a person in any of these categories is getting stretched pretty thin by now.

As we watch our legislators use the bodies of disabled children and adults and seniors like chess pieces in a game of wiping out what was once our robust public safety net and infrastructure, turning the keys to those kingdoms over to the highest bidder, whole systems collapse.

At least I know I am not alone.

*Liz Belile writes and teaches writing while raising her family in Austin. She is Co-Vice President of the Family/Guardian Association at the*

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*Austin State Supported Living Center, which celebrates its 100 year anniversary in June.*

*Bookmark Gray Matters. It could all be gone in the blink of an eye.*

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