

## Father fights for campus to thrive

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Stephen Joseph Gersuk struggled to keep a mammoth bag of puzzles out of the puddles as he walked from his apartment toward the pharmacy with his father, Stephen Gersuk.

Stephen Joseph, 34, had just finished his work gathering the outgoing mail from the many buildings clustered in the center of the 200-acre campus of the Denton State Supported Living Center, on the city's south side. Back in his room, he kept on his ballcap with the U.S. Postal Service insignia, but he changed his T-shirt, from one sporting a graphic of a mailman to another he got from SpiritHorse Therapeutic Center, where he rides once a week.

He was heading back to Plano with his dad for a visit. He gathered up some of his music collection and his backpack along with his puzzles before picking up the medicine he needed. Stephen Joseph, who has both physical and intellectual disabilities, would be spending some of the Father's Day weekend with the family.

"I hope he remembered Father's Day," Stephen's dad said, mostly to himself.

Did he?

"Father's Day. Yes," Stephen Joseph said, stopping in the doorway of his room. "Father's Day."

All boys need their fathers, even after they're grown. But Stephen Joseph needs his father just a little bit more.

He has been living in Denton for nearly 15 years. He arrived at the Denton State School after a stay at the North Texas State Hospital, a psychiatric hospital in Wichita Falls. Previously, he lived in a group home in Plano. A caregiver had abused him, beating him with a toilet plunger. His family didn't know he was in trouble until after he began spiraling down, putting holes in the walls at the group home by throwing himself into them.

The staff called the family to say they'd sent Stephen Joseph to Green Oaks Hospital, a psychiatric center in Dallas. Gersuk met his son there in a room with padded walls behind a metal door with a small window.

"We had to convince the judge to let us drive him to Wichita Falls, rather than have him ride in the back of a squad car," Gersuk said.

Stephen Joseph was born with Cornelia de Lange syndrome, a developmental disorder that affects many parts of the body, including speech and brain development, and can vary from mild to severe among individuals born with it. The exact incidence rate is unknown, but the National Institutes of Health estimates that it affects 1 in 10,000 to 30,000 newborns.

Compared to many others with the syndrome, Stephen Joseph's case is mild. But he will beat himself in the face until his nose is bloody when he's "had too much of the world," Gersuk said. In her application essay to medical school explaining why she wanted to be a doctor, Gersuk's daughter described her brother and growing up in a house that often looked like a crime scene, save the yellow tape.

"I never thought of it in those terms, but it was true," Gersuk said, adding he believed that was why she now works with children with traumatic brain injuries. "He changed all of us."

At the Denton State Supported Living Center, Stephen Joseph has his own room, decorated with family photos and posters of the Dallas Mavericks and all the characters from the Pixar movie *Planes*. His room is part of an apartment he shares with several other men. One of his caregivers, Toryan Baldwin, is never far away, nor is LaShounda Danough, as his job coach, when he's collecting the mail.

Gersuk says he recognizes that his son's care at the state supported living center is expensive. But he believes in the quality of life and the quality of the care his son receives at the Denton center. The hard-fought living arrangements Gersuk obtained for his son appear to be secure for now. And, he has dug in to help preserve the institution that has proven to be a warm and safe place.

"Man, you will fight like hell to keep that," he said.

The U.S. Department of Justice has been monitoring progress at all of the centers for nearly five years. The department sued Texas over conditions at the centers and a settlement agreement between them called for improvements in 171 standards of care.

The centers in Denton and Lubbock have made the most progress, but none of the state centers has met the Justice Department's requirements. The state Sunset Advisory Commission recently recommended that the center in Austin be closed and that state legislators identify five more for closure in the coming biennium.

Gersuk heads the Denton Center's Volunteer Services Council, which regularly raises money for "things we can't expect the state to pay for," he said.

For example, the council helped pay for new X-ray equipment for the center's dental and medical clinics, including a bone density scanner for patients who cannot lie on their sides. The equipment both increases residents' comfort and helps the center save on staff time, in part by avoiding a trip to a hospital to get a scan, Gersuk said.

Even though Comelia de Lange syndrome affects how the body grows, bone scans aren't something his son needs now, Gersuk said. But, after double-checking with the staff, he learned that Stephen Joseph would get a bone scan in about 15 years, when he turns 50, as part of his annual physical.

"I hope he's still here then," Gersuk said, mostly to himself.

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