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CARING FOR GABE

Providence Child Center workers make it possible for kids with profound disabilities to thrive



Gabriel Rader celebrates Christmas at the Providence Child Center. (Courtesy Providence Child Center)

Catherine Trevison
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When Gabriel Rader's mother was pregnant, an ultrasound delivered grim news. The baby's head was too small, the doctor told her. Gabriel's brain might not fully form. With problems this severe, he would likely miscarry, or die in his first year of life.

This year Gabriel Rader turns 14.

Though he is blind and nonverbal, and though he experiences seizures daily, he frequently delivers a smile so huge that parents Renate Rader and Matthew Taylor see it as an upwelling of joy.

These happy moments, Renate Rader says, are the gift of experienced care from a battalion of medical professionals including skilled nurses and nursing aids, developmental pediatricians, a neurologist, a dentist, physical, occupational and speech therapists,

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Renate Rader hams it up with 14-year-old son Gabe at Providence Child Center. (Courtesy Renate Rader)

an ear nose and throat doctor and pediatric neurosurgeons. Many care for Gabriel at the Providence Child Center, where he lives.

"I think we lucked out big time," his mother said. "I've heard horror stories of people just having to fight for their kids. If you are interacting with folks who haven't worked with medically fragile kids, it is hard for them to understand what they are dealing with, and what can be."

That understanding is essential for children who must rely on medical help to meet their most basic needs, such as eating via a stomach tube. Often the children remain nonverbal, and rely on caregivers and technology from birth onward. With advances in care, the children are living longer, healthier lives, said JoAnn Vance, director of children's developmental health at the Providence Child Center.

Every child has different needs, starting with communication. For one child at the center, caregivers might have to interpret eye movement; for another, hand position.

"I think typically folks think of them as newborn babies, but ... inside they are developing and growing," Vance said. "They will grow into most successful child they can be."

In Multnomah County, families are often referred to the Intellectual and Developmental Disabilities Division. "We're individualizing plans to that kiddo," with support ranging from in home care to adaptive recreation to help with rent or utility bills, said Alexis Alberti, the division director. "There are different cultural values, different social norms. It's not a one-size-fits-all model."

Gabriel's first major medical intervention came early, after a post-birth MRI showed that large parts of his brain were missing. But fluid was now pushing into that space, compressing his brain and enlarging his head. The baby was in pain and crying all the time until his pediatric neurosurgeon installed a shunt, allowing the fluid to drain into his abdomen.

More recently, Gabriel needed surgery to fuse his spine, which was developing a severe curve and compressing his lungs. Although the incision from the surgery extended all the way down Gabriel's lower back, skilled workers at Providence Child Center prevented any infection from his diaper and kept him comfortable as they weaned him off pain medicine.

"I can't imagine having to deal with this at home," his mother said. "A full spinal fusion at age 12 is a huge deal. I have these reminders often of why the staff at the center is brilliant and we're blessed."

Gabriel started living at the center before his second birthday, when his mother had to have her own back surgery. He is one of 17 full time residents; another 54 come only for respite care. Although parents like Renate Rader praise the center for providing an excellent quality of life, it has not been able to admit a full time resident for several years. Oregon's rules now favor keeping children at home or in smaller community settings, rather than in long term nursing care.

"We're moving toward a community integrated model. We want folks to live in their family homes and still get a level of care that meets their needs," Alberti said. "We look for the least restrictive level of care first."

At the end of last year, about 400 children qualified for intensive in-home medical and behavioral support through the state, said communications officer Tom Mayhall Rastrelli of the Office of Developmental Disabilities Services.

All providers say wait times for services shot up in the wake of COVID. Some caregivers pulled back, reluctant to see patients face-to-face. Some burned out. Others were lured by high salaries and nationwide competition for their skills.

Under a temporary emergency order, Oregon has been allowed to pay parents to take care of their children during the pandemic, Alberti said.

Gabriel's parents are now thinking about what their lives will look like when he turns 22 and "ages out" of life at the Providence Child Center. Could they find an adult facility that gives him everything he has now, like the staffer who makes sure Gabriel's craft materials include his favorite smell, black licorice? Could they bring him home, widening their doors and installing a hoist to help move his 110-pound body around? And what if he outlives them?

"There's a great amount of fear if we're not here to care for him," said Rader, who worries about how wars, fires and other major events affect the supplies that help keep her son alive. "There are so many things that go into keeping these kids healthy. ... You want them to have a good life while they are here."

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