

# Baltimore's CHILD

## Who's Taking Care of You? Respite for families with children who have special needs

Erica Rimlinger April 10, 2019 [Leave a comment](#)

On the surface, the Stroups appear to be a family of five. Tina and Trent Stroup have three kids: soon-to-be 15-year-old Addie, Oliver, 12, and Vivi, 9.



But one family member has a life-threatening and life-altering disability, and because of it, they must sometimes behave as a family of one. That one member, Addie, was diagnosed with Aicardi syndrome, a rare condition that can cause seizures, epilepsy and blindness. On the heels of that diagnosis came another: Addie also has autism.

“Everything,” Tina says, “revolves around Addie.” Daily family decisions are vetted through the filter of Addie’s health: “Can we do this today? Is she going to be able to go get ice cream? Nope, we can’t go because Addie had a seizure.”

The demands of caring for an individual with a disability can be physically exhausting, emotionally stressful and, perhaps hardest of all, unrelenting.

“For nine years, she didn’t sleep at all,” Tina says. “We literally didn’t get sleep. We would tag-team that: You sleep tonight, I’ll sleep tomorrow night.” “It’s been ups and downs for 15 years,” she adds, “many medications, many trials and errors.”

Tina and Trent sometimes just need a break. Tina wishes she could “turn my brain off.” And Addie’s siblings need attention, too. Tina wants them to “have a normal time like other families.” There isn’t enough time for the siblings to spend with both parents, and “there isn’t enough time for just him and me, definitely,” Tina says.

There are respite resources for families of children with disabilities. Some of them are readily available. Others are not. Ellen Galvez, parent and family liaison for the Baltimore County Public Schools’ Special Education Resource Center, says government respite resources are stretched thin. “In my experience respite is often desperately needed, but there just isn’t enough funding or enough qualified providers to go around,” she says.

But there are creative ways to find and think about respite, says Patricia Shepley, senior director of social work at the Kennedy Krieger Institute. Shepley has worked with families of kids with disabilities for 20 years and says the purpose of respite is essentially recognizing all family members’ needs and trying to find balance.

“One thing I tell parents is, ‘You are the mom car or the dad car. If you don’t fill the car with gas, the car doesn’t go.’” she says. “You’ve got to take that time out to refuel.”

The first barrier to respite is recognizing you need it. Shepley has seen parents subvert their own needs to focus on the needs of their child, even risking their own health and foregoing their own crucial medical treatments.

Mary Anne O’Keefe understands the health risks firsthand. O’Keefe, who lives in Middle River with her husband, Edward, and their 20-year-old daughter, Mallory, says the round-the-clock stress of unassisted childcare contributed a panic disorder, which, untreated, landed her in Shepard Pratt. She says when the burden of caregiving builds up, “it wreaks havoc on your mental health, your physical health, your relationship and your relationships with friends.”

“We could never just call Suzie down the street to watch Mallory,” she says. With her husband working nights, O’Keefe was Mallory’s sole provider. “When she got off that bus, she was all mine.”

Shepley says burnout risk increases with the complexity of the child’s medical needs and decreases with the availability of social support. Social support is a key indicator of family health. “If there are aspects of the child’s needs that cause them to be more isolated, they definitely are at risk for depression,” Shepley says. Caregivers should heed the warning signs of “extreme fatigue, feeling

isolated, feeling burdened, cognitive stress and not finding enough time to pay attention to other relationships.”

Shepley works with parents to figure out “how best to get regular, consistent care” and recommends parents identify and bolster their networks “both within and outside the household,” which can mean “one parent offering the other breaks” when possible.

The Stroups say they take this approach. Tina says, “We literally could not do it without each other. We tag team so much.”

“We take care of each other,” Trent says. “I’ll do stuff and then let her have time to go do stuff with her friends.”

Within the last year, they also connected with others at their church, Grace United Methodist, which has a special-needs ministry, which is “huge,” Tina says. “We’ve had a couple of my church friends get to know Addie so they can watch her. We have one babysitter on hand who really knows her and is comfortable with everything.”

Their family also uses the church’s respite care, which is offered quarterly and is open to the whole community. “We know that quarterly we’ll get three hours,” Tina says. “What we like to do is take our other kids and do something like a normal family.”

Sometimes camps are available for respite care. O’Keefe sent her daughter to a camp run by the League for People with Disabilities, Camp Greentop. “It’s a perfect amount of time for us and for her. We know she’s happy and safe.”

The Kennedy Krieger Institute runs Camp SOAR for its students and their siblings, allowing parents a full weekend off while knowing their child is being cared for by KKI staff. Chuck King has sent his two sons, Garrett and Jacob, to Camp SOAR for the past two years. King says when he and his wife dropped off the boys on a Friday night and went out to dinner afterward, they were struck at how rare this previously regular activity had become for them.

“It allowed us to, in a sense, breathe. And not have to worry for a change,” he says.

Whether families use a program or agency or find a babysitter on their own, Shepley says, parents should, of course, interview them and check references. “But probably the biggest thing that will help you feel comfortable is to have them spend some time with your child.

Have them come over and spend a day and go through the different routines. If there's a behavior protocol, make sure they're capable and open to learning that, and if there's a behavior therapist involved, they'll help with that training."

Another resource: Some movie theaters offer showings for families with children with autism. "The more they are able to participate in activities, the better," Shepley says. "That's what leads to mental wellness, the whole family being able to lead balanced lives."