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Sabrina's Parents Love Her. But the Meltdowns Are Too Much.

Unpredictable violence, chaotic outbursts and countless trips to the emergency room. What happens when an autistic teenager becomes unmanageable at home?

By Joseph Goldstein

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The other children were heading home after school. But not Sabrina Benedict. A progression of mishaps had sent her into a tailspin. Earlier in gym class, a much smaller boy had sprinted toward her, scaring her. Then a teaching assistant had deviated slightly from their usual goodbye routine.

Now mid-meltdown, she lay prone on the sidewalk outside her school, her legs dangling in the street. She was only 13 years old, but she was 6-foot-2 and 250 pounds, far larger than any of the teachers or school administrators who stood nearby, watching with concern. For a moment, the only sound was Sabrina's loud moans. She threw a shoe at a teacher. She took off her shirt. She cursed at the school staff arranged around her in a protective circle.

Summoned to the scene, her parents tried to soothe her. She kicked and swung until they backed off. On the Sabrina tantrum scale, so far this registered only a 4 out of 10, declared her father, Jeremy Benedict, who was pacing nearby. "It could go either way."

She might stand up, ready to go home. Or she might start smashing her head on the pavement. A knot tightening in his chest, her father focused on his breathing exercises.

This was the third time this week he had rushed to school for one of Sabrina's meltdowns. Lately, similar scenes had unfolded in doctors' offices, parking lots, Walmart, hospitals, on street corners and inside the raised ranch house where the Benedict family lives in Homer, N.Y., a town of 6,293 nestled in a valley near the geographic center of the state.

Sabrina, who was given a diagnosis of autism coupled with a rare genetic disorder, has exhibited aggressive behavior since she was a little girl. Now she towers over her parents. When she is happy, she gives them great big hugs, knocking them slightly off balance. When she is feeling shy, she crouches behind them. When she is frustrated, she sometimes hits them.

There have been so many 911 calls this past year that the family invited over several police officers and paramedics to meet Sabrina under more positive circumstances, when they weren't restraining her or strapping her to an ambulance stretcher.

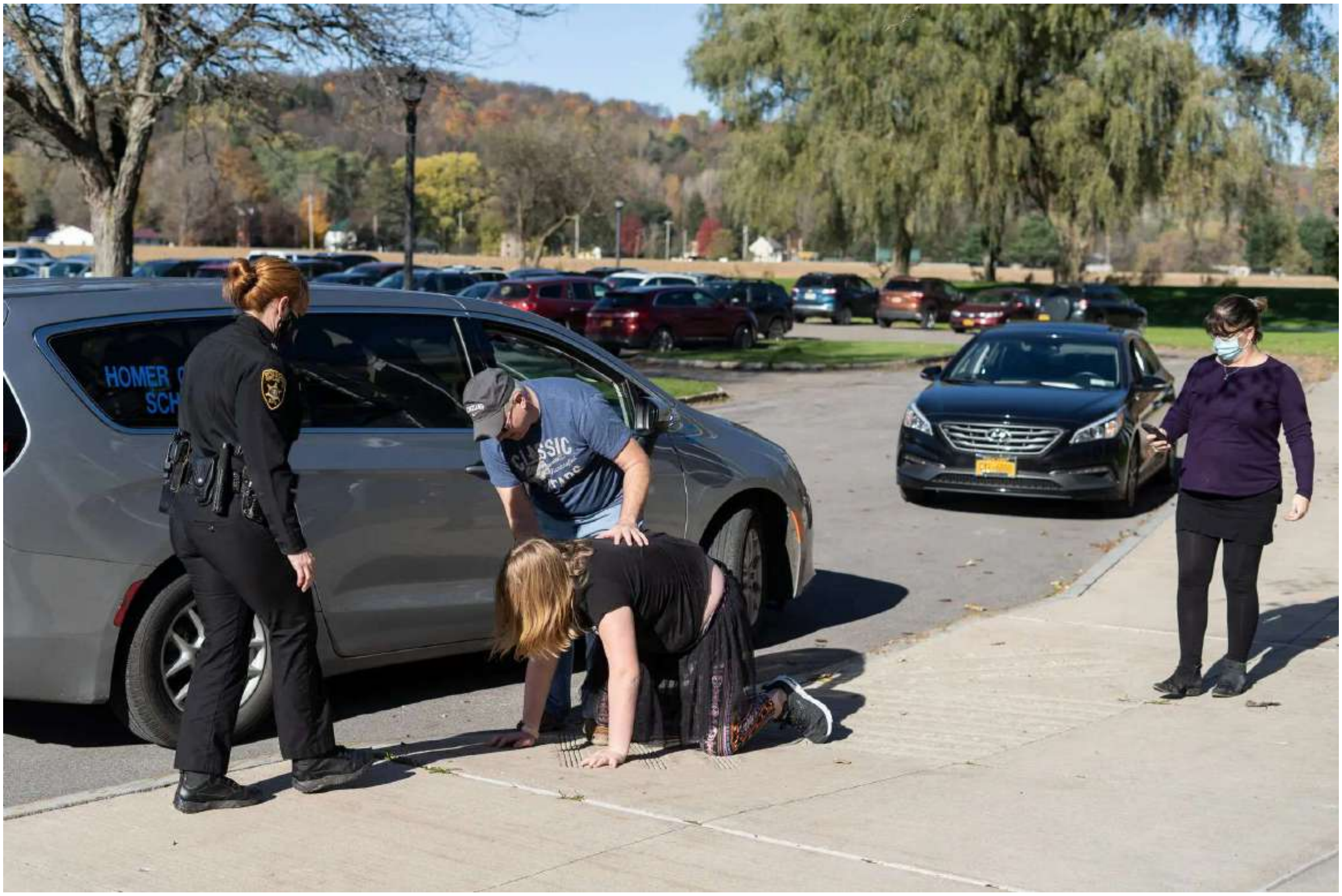
On that October afternoon outside school, Sabrina eventually calmed herself. It was just another day, soon difficult to remember, as Sabrina's outbursts accelerated.

There is no widely recognizable name for the crisis that has gripped the Benedict family. But dozens of New York families with an autistic child are struggling through a version of it right now.

What the children and their caregivers are going through is not new. By adolescence, or sometimes earlier, a small percentage of children with autism become unmanageable for their parents, and no amount of parental patience or devotion will change that.

The pandemic has made matters worse, drawing more families into crisis and deepening it for those already there. When New York shut down in March 2020, the carefully designed routines and support systems relied on by families of autistic children largely vanished. Without school and day programming, the behavior of many autistic children regressed. Some stopped sleeping through the night; others began harming themselves for the first time.

'We're not safe, and she's not safe'



Jeremy trying to calm Sabrina last October outside her school in Cortland, N.Y., near Ithaca. Her outbursts can be hard to control and even dangerous. Libby March for The New York Times

In interviews, parents across New York State described the same scenes of fear and helplessness: being attacked by an adolescent child, now bigger and more aggressive than before. The dread that their child might turn on a younger sibling. Their growing helplessness as their child's self-injuring behavior — relatively common among autistic children — escalates. The emergency room visits when there was nowhere else to go. And their eventual realization that the family home may be the wrong setting for their child.

A father in Brooklyn described his anguish at watching his autistic son smash his head repeatedly against the hardest nearby surface: the wall, the floor, the detachable shower head. A mother in Albany described her daughter's wild behavior: endless twirling, chewing on walls. Earlier this year, the girl was found in the yard with a broken arm, having either jumped or fallen out of a second-story window.

"One of the glaring weaknesses of the system is there is no real option for families whose children fall into that category," said Christopher Treiber, an associate executive director at the InterAgency Council of Developmental Disability Agencies.

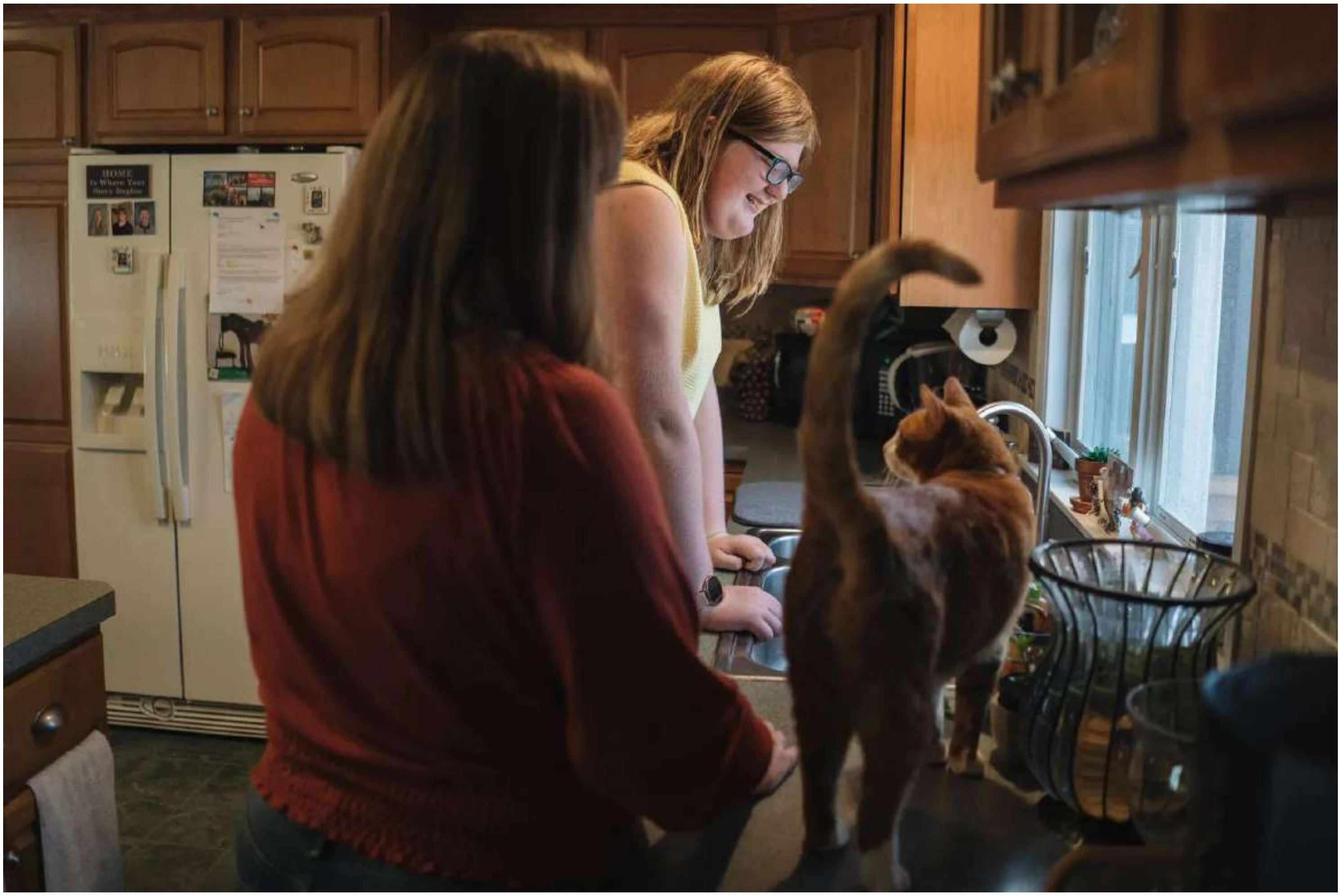
A half-century ago, many children with autism ended up in notorious state institutions like the Willowbrook State School on Staten Island, where those with developmental disabilities were left untended in filthy wards or strapped to beds.

In the years since these institutions were closed, there has been a clear presumption about what's best for many children with intellectual or developmental disabilities: They should live at home through childhood, attending special education classes and programs, eventually moving into group homes at some point in adulthood.

And for decades, this policy has kept families intact and provided richer, more connected lives for those with such disabilities. But the presumption can fail a small number of families like the Benedicts.

"We're not safe, and she's not safe," said Sabrina's mother, Crystol, who has sustained several concussions while trying to calm her daughter.

Where can Sabrina go?



Sabrina at home with Crystol. For decades there has been a clear presumption that many children with intellectual or developmental disabilities do best at home through childhood rather than being institutionalized. Libby March for The New York Times

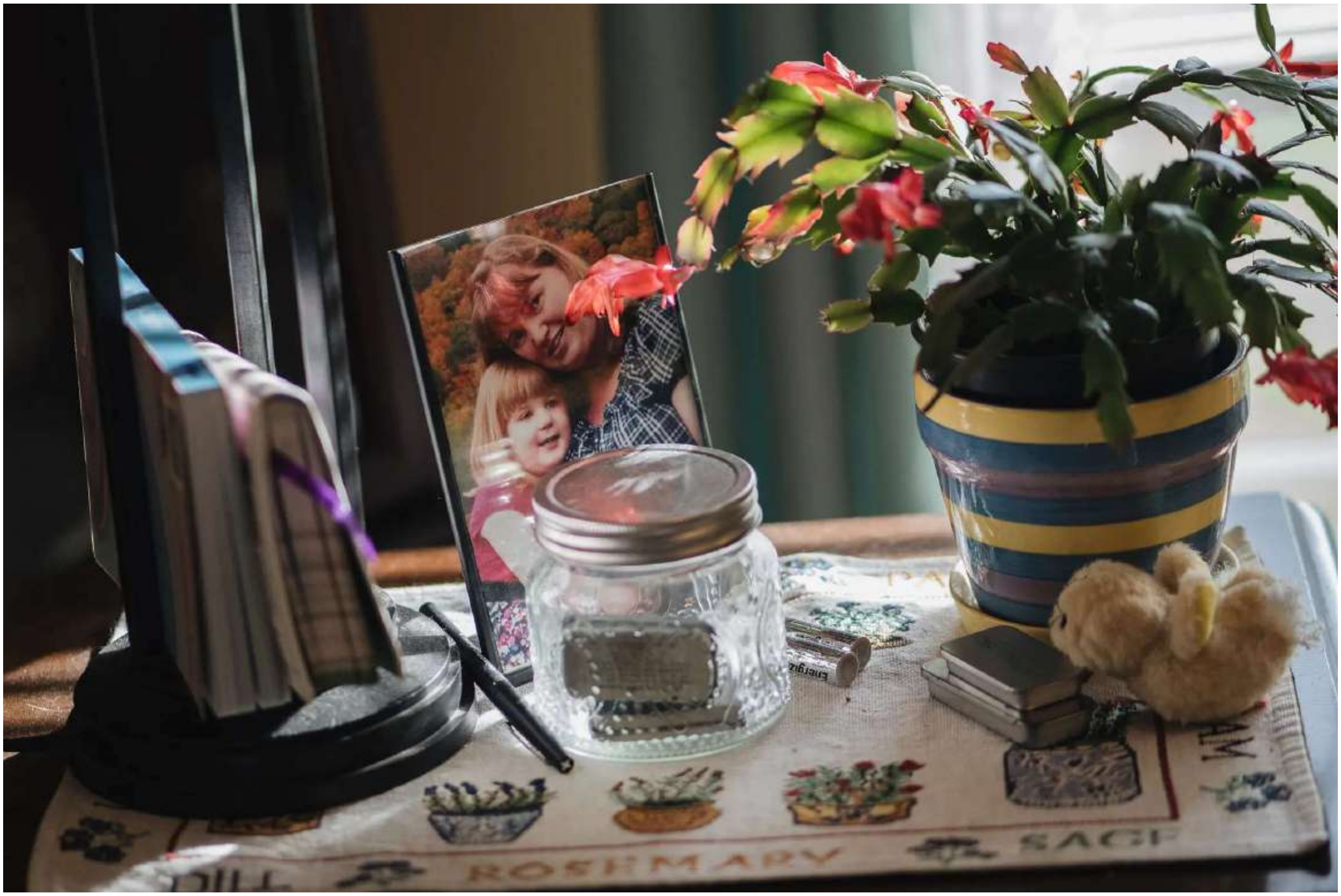
The state's answer to these families is to provide more support in the home. The Benedicts, like many people in a similar situation, were given a case manager and a budget to hire a home aide for their child. But a single aide is often unable to handle an aggressive teenager.

But if home life is untenable, where should Sabrina live?

In New York State, there are around 50 residential schools, mostly private and expensive, that specialize in working with children with disabilities ranging from autism to traumatic brain injuries. But the demand for spots is great, and these institutions are generally able to pick and choose whom to accept.

Each year, to meet this need, New York will pay, often grudgingly, for around 300 children with disabilities to attend out-of-state programs. Autistic children make up the largest share.

These programs have a range of reputations and therapeutic approaches. Some are widely praised. Others draw controversy, like the Judge Rotenberg Educational Center in Massachusetts, which uses electric shocks to punish and discourage dangerous behavior.



The Benedicts adopted Sabrina, bringing her home when she was just a day and a half old. They were not fazed then by the knowledge that her biological parents had intellectual disabilities. Libby March for The New York Times

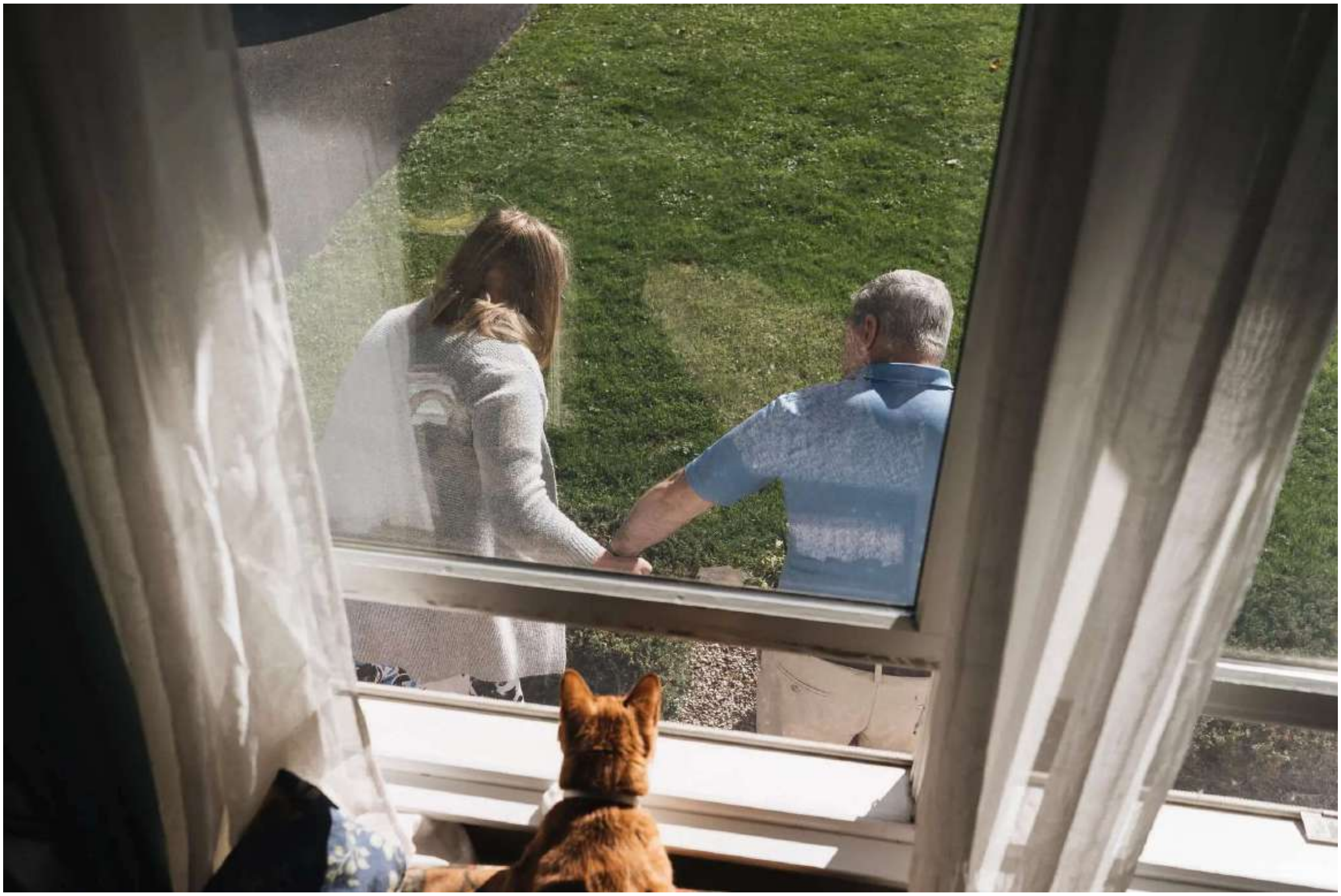
Still, these programs can be life-changing. Parents describe how their children, unmanageable at home, grew more communicative, resilient and happier and became less aggressive. They credit the structure and the rules the school provides, the responsive therapists and the experience of living with peers.

But gaining admission is a slow and sometimes adversarial process. The government can be reluctant to approve these placements, which can cost more than $300,000 a year — a cost shared by a local school district and other government agencies.

And placements usually happen only after a school district has proved unable to provide an "appropriate" education in a special education classroom. That can take months, even years. In this calculus, a deteriorating home life, like the one experienced by the Benedicts, receives relatively little weight.

By late last year, some 30 programs had rejected Sabrina. One objected to her "high level and frequency of aggression," according to a spreadsheet Jeremy keeps. Another stated: "Can't meet her needs." Another explained: "This youth would require 1:1 supervision in our milieu, and currently we are at max capacity in our milieu for youth who require 1:1 supervision."

'You know, nature took over'



Jeremy walking Sabrina to her school van. She clings to a routine, and any deviation can unsettle her. Libby March for The New York Times

The Benedicts still find happy moments in their home. Sometimes they play Uno together. Sabrina brims with enthusiasm as she shows her mother ballet moves, or talks about upcoming holidays, her favorite foods or her day at school. Or they flip through photo albums, remembering a vacation to Assateague Island.

One afternoon last year, Sabrina sat at the kitchen counter, drawing an intricate blueprint of a house where she imagined one of her teachers lived. When Crystol arrived home, Sabrina ran to greet her. Then she flopped down on the sofa in anticipation of a massage. Her mother knelt beside her. Crystol pretended to make a pizza on her daughter's back — kneading dough, spreading sauce and sprinkling cheese.

But within the hour, Sabrina would be overwhelmed with disappointment, frustration or an emotion she could not name. She would stomp her foot, hard. And begin to wail.

"Do you need help?" her father asked, his voice even, his eyes looking away.

Between wails, Sabrina announced, "I'm mad." But she shut down her parents' efforts to talk to her. "I hate you," she said. "Go away!"

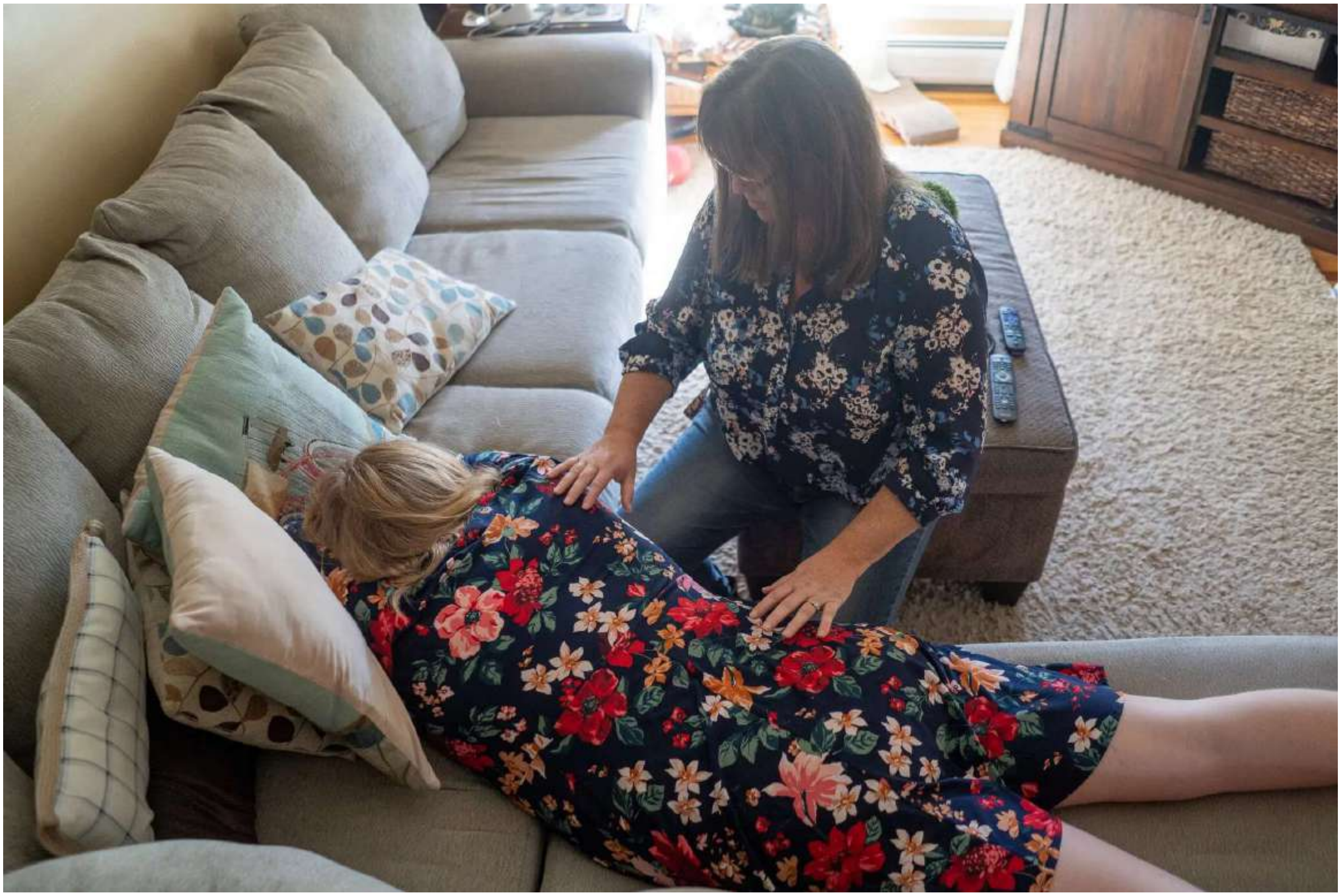
At times like this, her mother encourages her to breathe in and breathe out. "Smell the roses and blow out the candles," she says. And her parents stand there frozen, waiting for what happens next.

When Crystol first saw Sabrina, asleep in a bassinet at the hospital, she cried with happiness. It was July 2008. Unable to have a baby on their own, she and Jeremy had become foster parents, planning to adopt. They brought Sabrina home when she was just a day and a half old.

They were undaunted by what the foster care agency told them: Sabrina's biological mother and father both had intellectual disabilities, and the father had been arrested on sexual assault charges.

"We were hoping that it was nurture versus nature, and that nurture was going to take over," Crystol recalled. "But, you know, nature took over."

When Sabrina was 5, genetic testing revealed that she had a rare chromosomal deletion associated with autism and developmental delays.



In a soothing massage, Crystol pretended to make a pizza on her daughter's back: kneading dough, spreading sauce and sprinkling cheese. Libby March for The New York Times

By then, Sabrina's tantrums seemed different from those of other children. One of the first big struggles unfolded at the optometrist, when Sabrina was held down for eye drops. Afterward, she began kicking her mother and wouldn't get in the car until the police intervened.

A rotation of therapists and counselors visited Sabrina at home. One was so disturbed by what she saw — Sabrina, age 7, slamming into walls and chairs and people — that she urged the Benedicts to call an ambulance. Sabrina spent three weeks in a state psychiatric hospital, the youngest patient there.

By 2018, Sabrina was too big for her parents to pick her up when she flung herself to the ground and refused to get up. By the next year, she was taller than her father, who is 5-foot-10.

Sabrina is more verbal than many autistic children with similar behavioral difficulties. Sometimes after an episode she will tell her parents what triggered her. “I’m really proud of her for that,” said Crystol, who is a teaching assistant in a special education classroom. Though Sabrina’s meltdowns often erupted quickly, her parents had become attuned to what might set one off. What happened on a July afternoon in 2019 was more frightening. Crystol had been standing at the kitchen counter making her daughter’s favorite snack — a mix of nuts, pretzels and marshmallows — as Sabrina excitedly described that day’s kickball game at summer school. Then Sabrina’s tone changed.

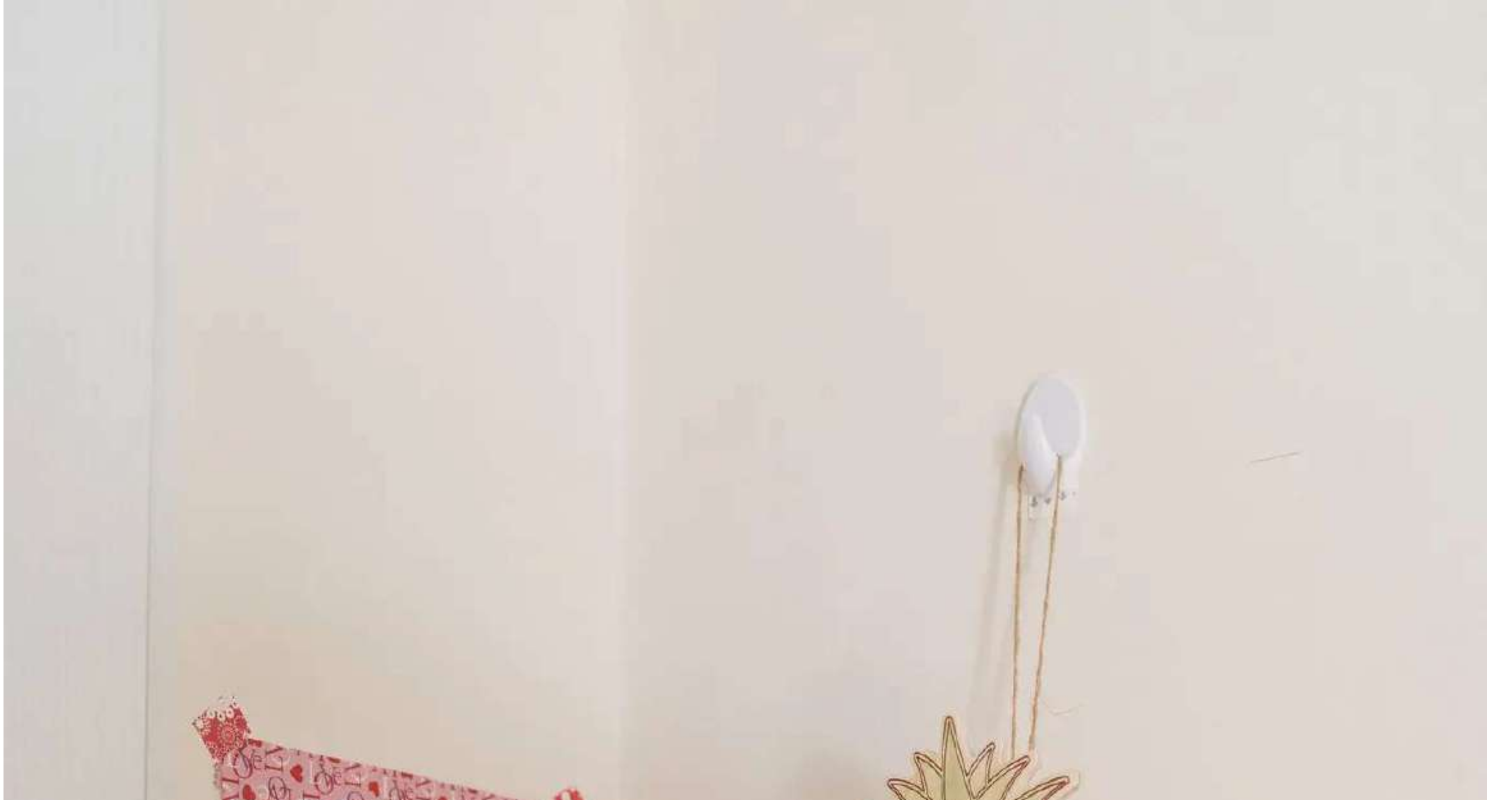
“I’m going to kill you,” Sabrina bellowed, before charging at her mother.

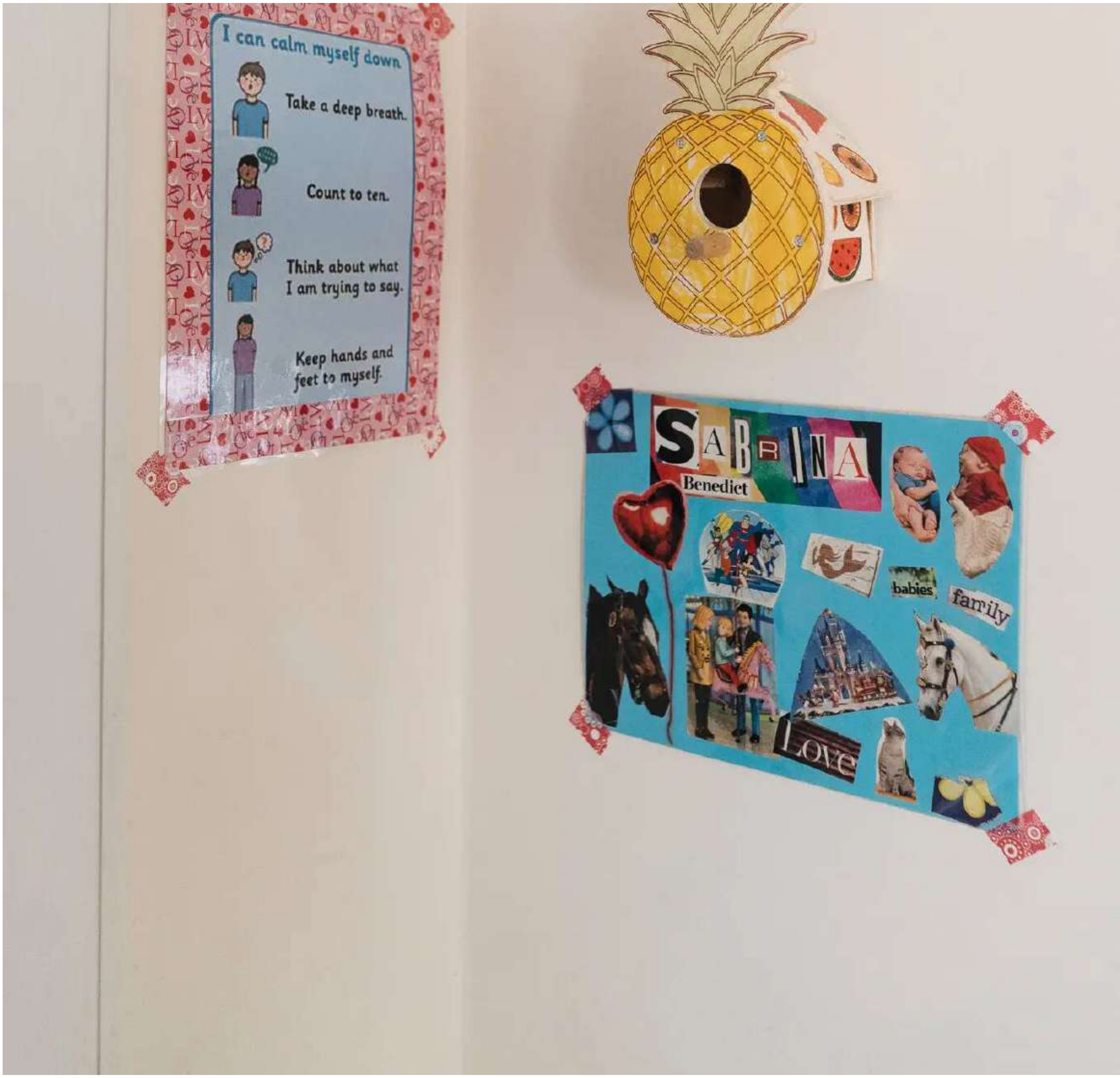
“The last thing I remember is her on top of me, hitting me,” Crystol recalled. When she regained consciousness, Sabrina was still on top of her. But now Sabrina was pounding on her mother’s chest and trying to revive her, clearly terrified.

Mother and daughter both went to the hospital, but in separate ambulances. Crystol had a concussion and a broken hip.

Sabrina, arriving in acute mental distress, would be hospitalized for 44 days. Not, according to the Benedicts, that the hospital had much in the way of treatment for her. That’s just where some autistic children frequently land.

Living in the emergency room





Sabrina’s art hangs around the Benedict household in Homer, N.Y. Libby March for The New York Times

They are taken there by the police after violent outbursts or by parents who don’t know what else to do. There is, parents and advocates say, literally nowhere else to take their children in an emergency. Though some return home quickly, many others languish in hospitals for months, rarely venturing outdoors and receiving little therapy or programming.

Decades after deinstitutionalization, some autistic children remain stuck in hospitals for lack of other options, and their parents are afraid or unable to bring them home.

Summer Ward, the 10-year-old girl who fell from the window, has been living on the seventh floor of Albany Medical Center for more than 100 days. According to her mother, Tamika Ward, as well as several others who have visited, Summer rarely leaves the hospital, which costs the county close to $3,000 a day. Summer’s broken arm has healed, but she remains in a hospital room because no residential school has yet cleared a bed for her and going home is no longer an option.

Similar accounts recur in hospitals across the state, according to interviews with parents, hospital staff and adults who work with disabled children. They describe autistic children and adolescents alone in bare hospital rooms, watching YouTube videos for hours and gaining 10 or 20 pounds or more from inactivity and antipsychotics. Often they spend their days on mattresses on the floor, the chairs removed so they can't be thrown.

At the University of Rochester Medical Center, a 10-year-old girl with autism and nowhere else to go spent more than 152 days there last year, according to the hospital.

"They essentially become institutionalized by living in a hospital," said Dr. Michael Cummings, a Buffalo psychiatrist, who works at Erie County Medical Center.

Dr. Cummings said that, given lengthy wait times for residential-school placement, families need more options beyond the emergency room. He suggested that short-term programs and group homes for children, as well as respite centers for families, could fill the gap.

For Sabrina, it was during that 44-day hospitalization that her parents began to search for a residential placement. Many government agencies were involved: the local social services department, the state's Office of Mental Health, the state Office for People with Developmental Disabilities. During lengthy conference calls, Jeremy marveled at the number of government agencies and social service providers involved. He once counted 26 people on a single call. "They're all here for us," Jeremy recalled thinking.

But he began to reconsider this impression as the weeks passed. It seemed to him that someone on the call was always playing defense, arguing that Sabrina wasn't the right fit for their services. He recalled someone saying her IQ — around 64 — was too low for one program. Others had different objections, sometimes singling out one of Sabrina's diagnoses and saying it made her a different agency's responsibility.

Sabrina eventually got a spot in a short-term program in Buffalo for children with disabilities and mental health problems. Some weekends, her parents drove three hours each way to visit. But the program would keep Sabrina for only about a year, and she returned home in the spring of 2021.

After that, there was a crisis of some sort every three days on average.

Most mornings, Sabrina made it out the front door to go to her special education school in nearby Cortland. But what happened after that was often unpredictable.

Would Sabrina get in the van to school or run down the street? If she got in the van, what would happen when she arrived at school? Would she go inside? Or bang her head against the brick wall? If she went inside, would she make it to her classroom? One morning, her teacher greeted her too emphatically, causing her classmates to all look at her. Sabrina retreated into the hallway and began to grunt.

Jeremy eventually quit his job in quality assurance and food safety at the local university so he would be available to respond to each crisis. He often ended up on the ground with Sabrina, trying to restrain her from banging her head against the pavement. Sometimes he had to immobilize her for 30 minutes or more, the two of them struggling on the sidewalk.

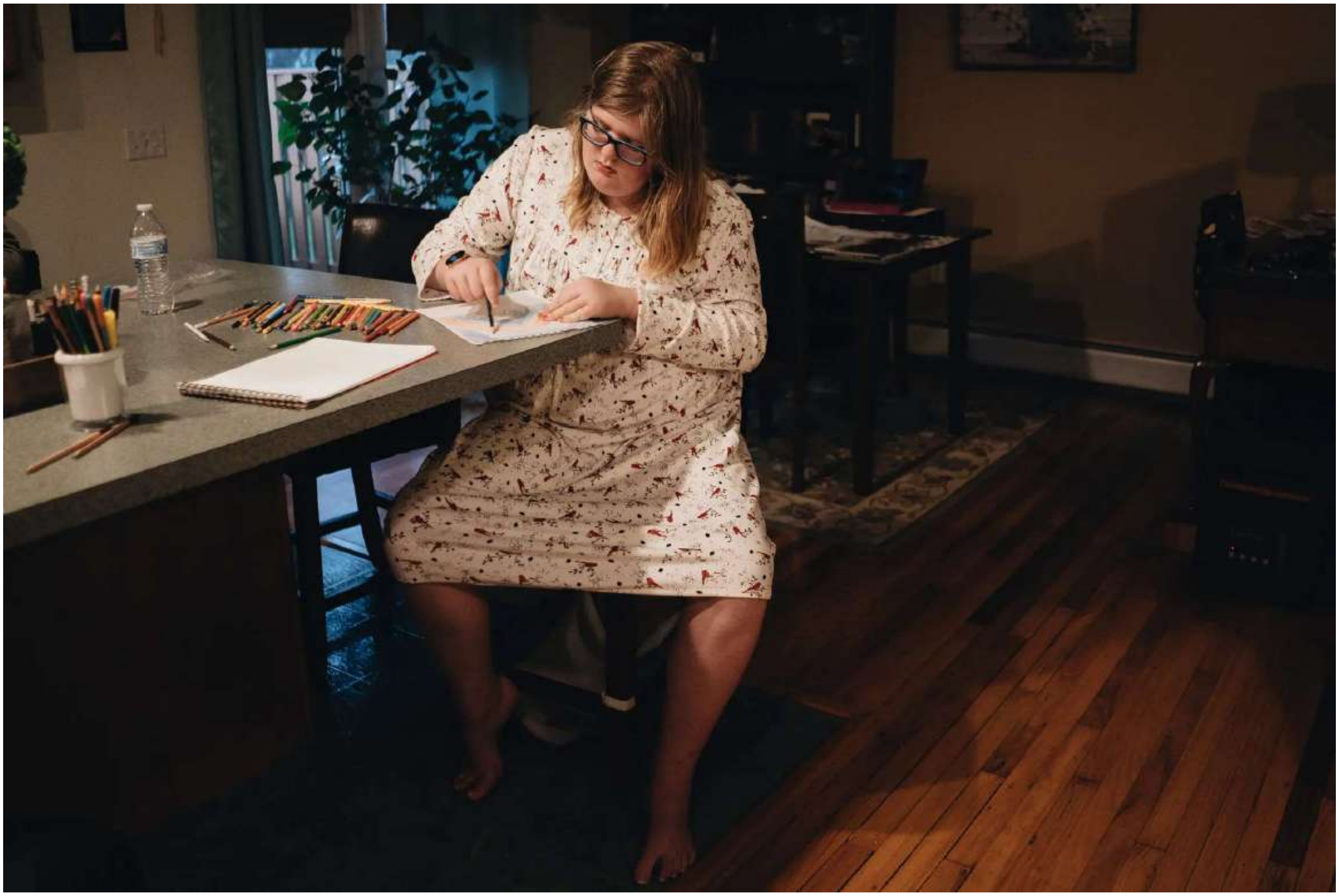
There have been desperate moments when Jeremy has almost wished he could go back in time and undo everything. "I'm guilty of saying it," he said. "I wish I had a time machine."

But Crystol and Jeremy would remind themselves that they were giving Sabrina the best life they could. “It’s gut-wrenching to think if we didn’t take her in and adopt her, what kind of life would she have? Where would she be?” Jeremy said. “That’s the oil that lights our fire and keeps us going.”

Last August, Crystol was struggling to buckle Sabrina’s seatbelt as her daughter was thrashing wildly, in the midst of a three-hour meltdown. It ended with Crystol unconscious from a blow to the head. It was her fifth Sabrina-induced concussion. Crystol thinks they have begun to affect her memory.

“Whether she knows it or not, I’m afraid of her,” Crystol said recently.

‘I want to go somewhere’



Part of the routine before bedtime: Sabrina draws at the kitchen island. Libby March for The New York Times

Sabrina has a very particular bedtime routine. First she eats seven saltines. Then she play-acts elaborate scenarios. Her parents encourage her to try out happier story lines, but during most of the past year, Sabrina’s bedtime play has often involved pretending to be a hospital patient. Instead of healing, she suffers one injury after another. And though she does befriend the nurses, she never leaves.

In December, a for-profit school in New Hampshire offered to admit Sabrina once it hired more staff members. It was the most promising news the Benedicts had heard since they began searching for a long-term residential placement in 2019.

“Boarding school” became the new bedtime game. Sabrina would imagine her first day there. She would get a key to her new room. She would open the door and meet her new roommate.

But as the weeks passed, the school kept shifting the timeline for when Sabrina might start. It might be another nine months. Jeremy and Crystol did not think they could make it that long.

As they played “boarding school” with Sabrina, her parents wondered if they were all preparing for the biggest change of their lives or just playing an imaginary game.

In January, Sabrina ran away from school yet again. It was bitterly cold and the roadside standoff took longer than usual. Afterward, Crystol couldn’t stop shivering.

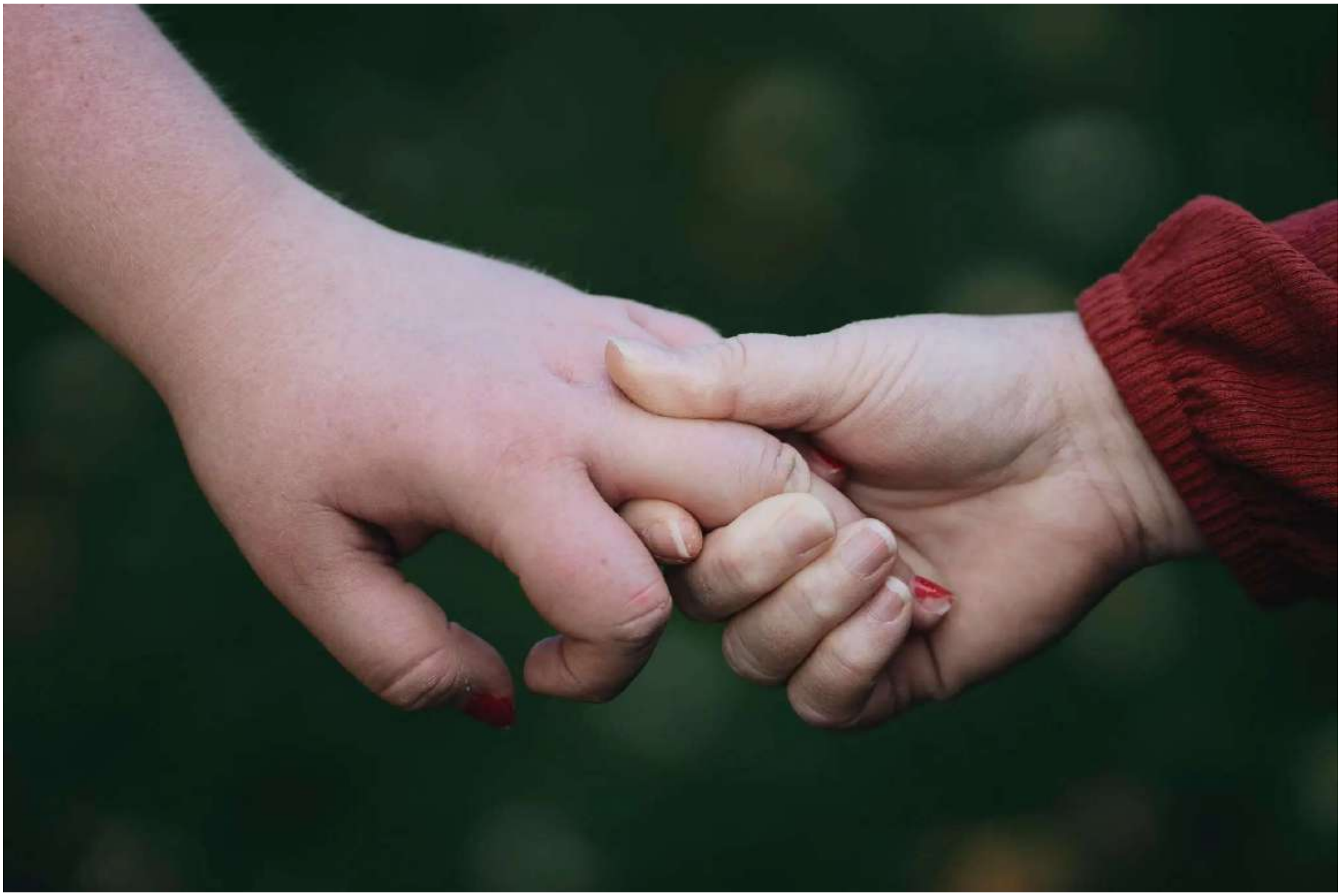
Back home Sabrina refused to change her clothes, which she had soiled. So they struggled some more. Her parents worried she would get another urinary tract infection: Some years, Sabrina had 10 or more, and they often ended in the emergency room, with Sabrina in restraints, screaming as a nurse injected her with sedatives or antipsychotics.

Later that night, Crystol told Jeremy that if he wanted to leave, she would understand. It took a moment for him to realize she meant *leave*, as in the family breaking apart.

By February, a different residential program — this one in Doylestown, Pa. — had offered Sabrina a spot. The online reviews didn’t inspire confidence, but the Benedicts felt reassured after speaking with administrators.

After a few delays, that program, Foundations Behavioral Health, called with a start date: March 28. That month, Sabrina ran away from school once more, getting half a mile down the road. As a police officer blocked traffic, Crystol tried to coax Sabrina into the family van. “I need help,” Sabrina said. “I want to go somewhere.”

There is this place called Foundations, her mother said. “If you come with me in the van, we can talk about it.” Sabrina followed.



The Benedicts were torn about seeking a residential program for their daughter. But Sabrina wanted to go. “I need help,” she said. “I want to go somewhere.” Libby March for The New York Times

In subsequent days, Jeremy and Crystol worried that the breakdowns might accelerate as the departure neared.

The guilt they had felt two years earlier when they began looking for a residential placement had long ago dissipated. They wanted Sabrina to have days that were defined by more than struggles and havoc. “She’s been ready for a while,” Crystol told herself.

As the start date approached, Sabrina packed and repacked her bag a dozen times. Allowed just one comfort item, she took a hard look at her three favorite dolls.

At bedtime on her last night at home, Sabrina reached her hands far above her head. “I’m this excited.” Then she held them out in front of her, about a foot apart. “And I’m this nervous.”

In the weeks that followed, Jeremy found a sales job. He and Crystol began to leave home more often. Sometimes they ate out together or strolled calmly down the aisles at Walmart. They had become so isolated, cut off from friends and family.

On one of her first nights at school, Sabrina refused to go to bed and became aggressive, leading staff members to restrain her forcibly, according to Jeremy. Another night she fell in the bathroom, hurting her ankle. And there was another child who seemed to be bullying her, tripping her and hitting her with a stick.

But somewhat miraculously, this has not derailed her. She likes her roommates and the classes, particularly art and dance. She has shown patience and empathy to other children, including a nonverbal classmate who got into Sabrina’s toiletries and ate her deodorant.

Jeremy and Crystol visit Sabrina every third or fourth weekend. And each night Sabrina calls home around 7 p.m. That call has become the focal point of her parents’ day, the moment they look forward to and then grow apprehensive about as it approaches.

Sabrina never fails to describe what she had for lunch and for dinner. Most evenings she will say: “I had a good day, I’m being good, I didn’t have any issues.” And very recently, she has started adding, “And I’m not just saying that to make you feel better.”

The calls are brief. But most nights they are so reassuring they leave her parents almost giddy.