

Luke's Best Chance: One Man's Fight for His Autistic Son

More than a million children in America are on the autism spectrum. What happens when they come of age?

By Paul Solotaroff

2 hours ago

Luke greets me in the hallway, thrusting a book in my direction, then snatches it back and darts into his room. It's been two weeks since I've seen him, and what I desperately want to do is grab him up and hug him till he howls. But because it's been two weeks – and because he is autistic – I must begin again, from the start line, with my son.

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His bedroom, per usual, is a hot mess. The floor is a Slip 'N Slide of books he's pulled down, most of them in greasy tatters. *Clifford's First School Day*, *Clifford and the Big Storm* – whatever that brave dog is put through by his author is nothing compared with the carnage he suffers at

the hands of this rabid boy. The huge stuffed Clifford my fiancée bought for Luke is splayed on his back, paws up; he is draped in laundry that appears to have been folded by someone without patience – or fingers.

Washing his own clothes, then putting them in drawers, are among the "goals" set forth for him by the ever-changing staff at the residential school he now inhabits. But in the two years since he left the separate dwellings of his divorced parents and moved to an institution on Long Island, he has taken just the most incremental steps on the path to self-maintenance. At 17, he still requires someone to bathe him and wipe up after he toilets; to cut his food into chewable pieces and see that he eats with a fork, not his fingers; and to hold him with two hands while crossing the street on outings to the movies or museums. Luke is as much a threat now to dash into traffic as he was as a headstrong child back in grade school. But he's grown half a foot since we moved him here and checks in at almost five-nine; anyone daft enough to restrain him one-handed is playing with kitchen matches at Fukushima.

His back to me, Luke hands up *Clifford's Family* with a one-word injunction: *Veed!* (Translation: Read till I say stop.) This is step one in the wooing I must do to get back in his better graces. Anytime my job takes me away for a stretch, I pay for it in his baleful disregard. Since the time he was six, he has come to know his father as a man who loves him and leaves him. There was no way to explain then why I had to move out when his mother and I split in 2005, both of us pushed to the breaking point by his 2 a.m. wake-ups and the constant siege of crises he presented. No one can prepare you for the fatigue of a first child. But when that child gags constantly on fistfuls of food; when his eyes roll back in a vacant haze that will belatedly be treated as seizures; and when, for the umpteenth time, he breaks a new DVD player the instant you look away – well, that isn't fatigue, it's slow death. As much as I craved our tactile closeness – the softness of his cheeks when I pelted him with kisses; his post-bath scent while we snuggled, watching Elmo – it was do-or-die for me by the time I left. At great personal cost, I saved my own neck, and lost some part of him that I'll never quite recover.

I sit and read to Luke now in the semidark, going slowly so he can pipe in words he knows. They often keep the blinds drawn in this newly built complex, though my ex-wife Elaine and I have urged the staff to raise them every morning. We also ask repeatedly why these kids are stuck indoors on a crisp, dazzling day in early spring. "There's a farm down the block," says Elaine, "where he could learn to plant seeds and water crops." Maybe that would happen if the school could retain its workers, but in a high-stress job, dependent on Medicaid funding, the turnover here is constant. This is hard on the managers, who must constantly find replacements, but harder by far on the children who live here and keep trying to trust adults who disappear.

Meanwhile, Clifford's working his juju on Luke. As I read, he bounces on his bed for joy. Snatching the book away, he hands me another – then, two pages in, yet another. This is my boy: an ebullient toddler who's three months shy of voting age. With his energy and sweetness, he charms everyone who meets him, then drives them up a wall with his global needs.

I change him out of the pants he's in to a new pair that actually fits; for four hours, he'll trade the monotony of this place for lunch at the meatball parlor he loves, then an afternoon of bowling and bookstore shopping. I live for those hours, and I dread them, too. By the end of the visit, I'll be whipsawed by feelings that carve old ruts in my heart. There's the guilt of dropping him back off, after he's warmed up enough to let me kiss him. There's the grief I must work through over his painfully small progress, and the doubts that we were right to send him away. And

overhanging those are my master emotions: the panic and confusion about what's next. Three autumns from now, Luke will age out of school and go hurtling off the cliff called "transition." The day he turns 21, he will lose his legal mandate to the government-funded care for disabled kids. Something will replace this – a shared room in a state-run group home, or a terrifying arrangement in which a flat is rented for him and his staffer leaves the moment Luke's off to sleep.



Paul Solotaroff and his 17-year-old son Luke, at home this July. Gillian Laub

And so – the clock ticking – I set out last winter to seek a third way for him: a place or a program for profoundly impaired kids that provides them more than shelter and hot meals. The search, however selfish, had a messianic bent. There are more than 1 million children in America with autism, and 3 million more with other intellectual or developmental disabilities. Many, if not all, of their mothers and fathers are kept awake nights by two worries: How can I give my child a life worth having, and where will she/he live when I'm dead? There is no peace for us till we've settled those questions, not an inch of separation from the gnawing dread that we'll leave them alone and undefended.

Happily, after much hunting, I found precisely the place for Luke and kids like him: a thriving community of young adults who've evolved beyond their parents' wildest dreams. Set on the North Shore of Massachusetts, it's close enough to me that I could drive there in four hours; it houses adults for tens of thousands less than what a group home would cost, and can quickly be copied in other states. Having seen it, I'll accept no substitute: It is there that Luke's life and learning can begin. But to get it, I'll have to move heaven and earth, fighting a vast bureaucracy that functions to deny parents the one decent choice they have.

In the mid-1980s, the rate of kids with autism was roughly one in 2,000. Thirty years later, it is one in 68, per the Centers for Disease Control. Experts agree that improvements in diagnoses account for some of that surge, as does the expansion of the term "autistic" to "autism-spectrum disorder," which includes behaviors once called something else. At that point, though, consensus stops. A study published last year by clinicians at Penn State declared that the radical increase in reported cases was almost entirely an accounting issue. But researchers in

Seattle and Denmark dispute that, saying semantics are only part of the story. "There is this portion of an increase that is not accounted for" by diagnostics, Annette Estes, director of the University of Washington's Autism Center, has said. Stefan Hansen, who co-authored the Danish study, found that 40 percent of new cases aren't explained by "administrative decisions." That split is an apt snapshot of where things stand in the third decade of the Age of Autism: We can't even agree on the size of the problem, let alone tease out its causes.

"Our current theory is that autism is many disorders and will turn out to have hundreds of triggers," says professor David Mandell of the University of Pennsylvania's School of Medicine, the country's go-to researcher in autism services. Asked how far we are from a working grasp on how, when and why the syndrome happens, Mandell was both hopeful and vague: "If the finish line is imagining techniques that let us see it at the cellular level, we're in lap 250 of 500. But not all laps are driven the same, and the one we're in now is long and slow."

Forty percent of autistic children never learn to speak. Roughly half engage in aggressive behaviors, either against their caregivers or themselves. These aren't likely to be among the 10 percent with so-called savant gifts who go on to do great things in arts, science and engineering. Nor are they the fraction, substantially larger though uncounted, whose high-end functioning allows them to work and find their own way in the world. These are the other kids, the sizable percentage who don't make sudden strides or outgrow symptoms. They are the boom generation of the cognitively disabled: kids like mine, who are taught, at great expense, to fold a towel and eventually tie their shoes.

And then they turn 21 and an odd thing happens: Collectively – *poof* – they disappear. "Kids have federal rights to 'a free and appropriate education,' but no mandate to anything after that," says Desiree Kameka, director of community engagement and housing network for Madison House Autism Foundation, a matrix of housing and service providers for people with intellectual and developmental disorders. "Fifty thousand autistic kids are aging out a year now, and the great majority go home and get no support: no job training, therapy or socialization."

As adults, they must apply to their states for help and clear a series of tall hurdles to get it. State agencies are supposed to assess them while they're still students for the care they'll need as adults, but often fail to do so or set the bar so high that few qualify for Medicaid-funded help. That's because it costs at least \$2 million to support an autistic person with intellectual disabilities over a lifetime, and states are responsible for roughly half the tab for any adult they support. (The other half is paid by federal Medicaid.)



Illustration by Brian Stauffer

Without calling it such, states quietly ration care by placing the mentally impaired on waiting lists. In states like Texas, Ohio and Florida, the wait period for a Medicaid slot can be several decades long. In New York, that list is 12,000 deep. "There are almost 5 million adults with intellectual disabilities, and barely 20 percent get any funding [for residential support]," says Kameka. "They just sit around, regressing and getting sicker."

Had my son been born to a different mother and father that might have been his lot too. He has Fragile X syndrome (FXS), a genetic disorder that affects brain development in about one in 4,000 boys; like roughly half those boys, he is also diagnosed with autism. FXS is a condition that rings all the symptom bells, wreaking severe cognitive damage, chronic mood and sleep dysfunctions, and extreme sensitivity to light and noise. While his moods have stabilized on an antipsychotic (Abilify), there's no effective drug for his sensory overwhelm and severe attention disorder. For what it's worth to us, we'll never know his IQ. He's incapable of the focus and patience required to sit for an hour exam.

Still, because we fought for him at every turn – badgering the board of education for every treatment he was owed; beating the bushes for a social-work firm that got him Medicaid after a five-year struggle; and suing for a seat in private school, then placement, two years later, at this campus – our son has certain rarefied rights upon his graduation. He is one of the lucky few with a Medicaid waiver, which entitles him to a menu of funded services for the rest of his life.

The most important of those is housing support, though in New York, that's, at best, a mixed blessing. Unlike in other states, where there's an array of options for the fraction of adults who get waivers, Luke has essentially two choices. He can live in a group home, or an Individualized Residential Alternative (IRA), as the state now prefers to call them, with two other severely impaired adults, and spend his weekends and evenings doing what he does now: watching *Clifford* videos alone in his bedroom. That path is wasteful in every sense of the word. It costs New York around \$120,000 a year to house a child like mine in a group home, and another \$26,000 for a day-hab program, where he'd sit in a church basement doing puzzles all morning

while whining for his Kindle Fire. There are 35,000 adults in group homes in the state, or about one-sixth the total number in the country. Small wonder New York spends almost \$11 billion each year on its disabled clients, which is 40 percent more than California, the next-most profligate state.

For obvious reasons, then, the state has begun pushing a second, less prohibitive option. Self-Direction is a newish, person-centered plan that allows a family or a support agency to build a program around a child. For about half the outlay for group-home/day-hab, the state routes money to parents, through a broker, to rent their child a small apartment (or a room in a shared house); to hire staff to be with him throughout the day and/or help him find part-time work. But this kind of parent-run Self-Direction, now in its fifth year, is still tiny: Only 3,000 families have opted in, of the 80,000 getting some funding. "I can tell you firsthand why no one's doing this: It's the end of your life as you know it," says Christine Reel Brander, sitting on the terrace of her tiny row house in the Dyker Heights section of Brooklyn. "In the five years that we've done it, we've both aged 20 years. I can't wait till we leave New York. We're just . . . done."

Christine, a registered nurse, and her husband, Matt, a detective with the NYPD, are talking to me with one eye trained on their 27-year-old autistic daughter, Kimmy. She is having a good day, sitting peaceably with her iPad, rocking softly in her chaise and occasionally giving out a happy squeal. But there are wraps on both her ankles, and she can barely walk, having had a bad reaction to her diabetes meds. Maintained since her teens on a cocktail of antipsychotics, she is 50 pounds overweight and disposed to manic fits, during which she's kicked and punched holes in her bedroom walls. Self-Direction pays most of the rent for her apartment nearby and a staffer to supervise her during the day; it doesn't, however, pay for someone to watch her after she goes to sleep. And so her mother runs over after work to feed and bathe her daughter, then sleeps on a pullout couch there Sunday through Thursday. "My husband and I are ships in the night; we've barely seen each other the last five years," says Christine. "I bring her back over here Friday through Sunday and Matt's great at helping out then, but when was the last time we got a break?"

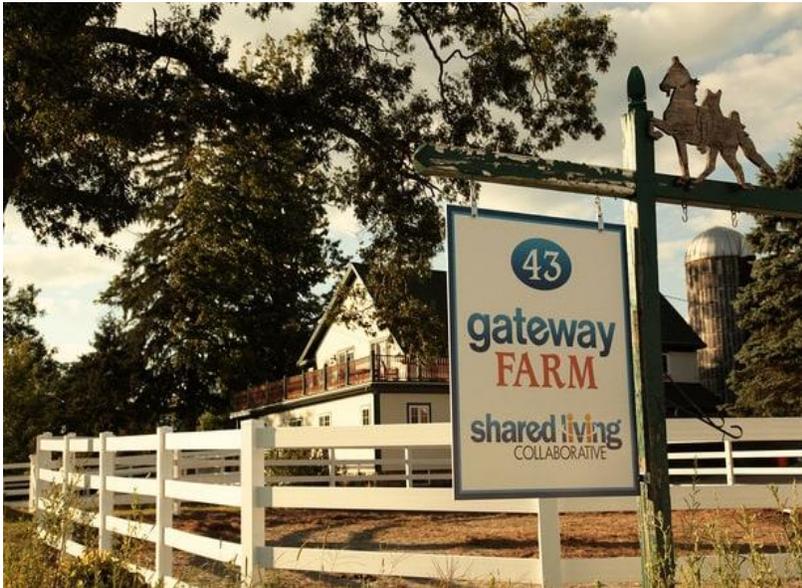
Matt, nursing a beer, gives a bitter laugh: "It's been 10 years since we even had a weekend."

When she aged out of school, Kimmy had some language; now, it's all but gone. Lonely and bored, she rarely leaves her house during the week. When a staffer calls in sick or has an emergency, Kimmy's care lands on her mother. "Six years ago, they promised us a group home; six years later, we're still waiting for them to build it," says her mother. If that doesn't come to pass, the family will pull up stakes and buy a tiny farm in North Carolina. They'll forfeit Kimmy's funding – Medicaid waivers aren't portable – and go to the end of their new state's waiting list. "But at this point, I've stopped caring," says Christine. "If we don't move, we'll both have heart attacks – and she'll wind up in a nursing home."

At the other end of Brooklyn, Mary Clancy follows me into her cramped apartment in Carroll Gardens. Like Kimmy's parents, she has the hangdog pallor of the chronically underslept and overburdened. Mary, a painter, and her husband, Richard, a laid-off lawyer, have sold everything they owned, including their loft in Soho, to pay for their autistic son's treatments. It worked, to a point: Eric, 24, can speak after a fashion and is a graphic artist whose work sometimes hangs in galleries. But his sentences don't always connect, and he can't be left alone for more than an hour or so. "He could turn on the stove and wander away – he spends hours in our yard, just pacing and humming," says Mary. Medicaid pays for his daily art class in Manhattan, and Self-Direction covers his chaperone there and back. But there's no room in his

funding for both the classes and an apartment, and his parents are so financially burdened that they can't afford a night out, let alone pay a second rent. The toll of being home with him has essentially broken his mother. "I'm not even 60, and all my systems have fallen apart," she says. "I have had over 20 surgeries and take eight medications a day."

"Her doctors agree it's stress-related, essentially PTSD," says Richard. "We know so many parents who are chronically ill. They work all day, then come home to these kids. The strain and the worry, it never stops."



The Gateway Farm Shared Living Collaborative in Massachusetts offers an alternative to institutions. Megan Hill

The Clancys also have a daughter, a high-achieving teen in her last year of high school. In a year, she'll be off to college, and Mary hopes to leave the city and follow her artist friends to the Hudson Valley. But even a rented house in an affordable town like Newburgh won't solve the Eric problem. "Too 'high-functioning' to get into a group home, and too low-functioning to live alone – basically, we've got him till we die," she says. "How is that fair to anyone, least of all him? He's the loneliest kid I know, and it breaks my heart."

If she lived in a nearby state, she'd have a path forward: a rapidly growing program called Shared Living. It recruits and trains providers – usually families or empty-nesters – to house autistic youths as long-term lodgers. It pays them well, covers most of the youths' expenses and connects them with a therapeutic job site. New York has a stripped-down version called Family Care, but only serves 1,900 of the 38,000 New Yorkers currently using some form of residential support. Vermont has moved a third of its eligible adults into Shared Living homes; in New Hampshire, the number is 40 percent. Neither do it as well, though, as Essex County in Massachusetts. There, one woman has perfected the model and created a human greenhouse for these kids. Daniela Morse takes youths like mine, plants them in fresh soil and adds just the right mixture of staff and nutrients to coax growth from kids who no one thought would bloom. I would pull up stakes tomorrow and eagerly entrust our son to Morse's care. But Medicaid won't allow that; his waiver can't cross state lines. It is the honey trap countless families find themselves ensnared by: Stay in a place where your child hasn't thrived, or move someplace where he might and go bankrupt.

On a chapped, snow-blown morning in January this year, I stood in the doorway of a barn in Massachusetts, watching young adults with autism and other impairments tend the horses and donkeys. Wearing ski gloves and snowsuits, they kibitzed with each other as they mucked the stalls and laid down mats of bedding. There were a dozen or so guys trundling in and out of the stables. At some point, each of them stopped what he was doing to come over, shake hands and say hi. As we fumbled with small talk, I felt my throat thicken: Not once in his life has my child greeted me as I walked through the door.

"You're looking at guys who were terrified of strangers," says Daniela Morse, her barn coat flapping open. "Many of them barely talked when they came to us. Now, just try to make them stop!"

Morse, 53, is a tall, jut-jawed blonde with an outdoorswoman's indifference to the cold. Nine years ago, she started a firm called the Shared Living Collaborative (SLC) out of her garage in Merrimac, Massachusetts. Having worked for two decades with a variety of kids in crisis, Morse set out to serve the ones otherwise bound for institutions: those with extreme behaviors, multiple diagnoses and psych-med regimens reaching back to grade school. "These aren't scary kids, they're kids who are deathly scared; they've been traumatized over and over," she says. "We don't try to fix them, we try to fix their environment. If you manage that, then the behaviors can fix themselves."

For the first several years, she eked out a living matching youths with providers in the area. Some kids were autistic; others had unspecified intellectual disorders, with complicated histories of abuse. Morse gave extensive training in managing behavior and solving crises to the families that took them in, and offered the youths' parents a broad choice of households, looking to make a match that might last decades. She connected a caseworker to every home, checked in often and gave the providers ample time off to travel with their families and recharge. The local disability office sent her more kids, delighted with the gains her charges were making – and the tens of thousands of dollars she was saving a year on average, per client, on a group-home bed.

Morse rented a bigger office and began adding staff. She soon noticed, however, that her workplace was crowded with youths suspended from their job sites for acting out. "They were bored out of their minds, and who could blame them?" she says. "Would you want to be stuck at a table all day, stuffing envelopes?"

A friend of a friend mentioned he had a small farm to lease, with a couple of riding horses and some chickens. Morse drove to Amesbury, the next town over, and felt a sense of peace while walking the spread. She started planting crops there in the summer of 2010 and taught her clients to ride in the outdoor ring. As the kids cribbed the basics of animal care and woodwork, their language improved and their meltdowns diminished; they began making friends with one another. By 2012, Morse's client list had tripled, and suddenly she had the wherewithal to buy her own farm – then a second one. Virtually everything on those farms except the offices has been razed, rebuilt and restored by her crews. The paddocks, chicken coops and greenhouses: all of it done by men and women who no one thought capable of focused physical labor and carpentry.



Daniela Morse has run the Gateway Farm Shared Living Collaborative since 2010. Megan Hill

These days, Morse is managing 90 clients, plus 50 adults who work there but live at home or in supportive housing, and growing her full-time staff to 70 workers. She opened up the Share Cafe downtown, where her clients cook the produce from her farms to serve crews and staffers wholesome lunches every day. On the same block in Merrimac, she morphed an office into a studio that trains dozens of clients to design and weave textiles that they sell at local fairs. She opened a co-op studio to teach ballroom dancing, and recently added two new farms. At each of these sites, I caught glimpses of Luke: boys with his horsy, loping gait and his furtive, sidelong smile. My heart skipped to think of him working beside them, absorbed for a couple of hours in honest labor.

"We're training guys to handle money and talk to shoppers – that's the integration I believe in," Morse says. "You can't send autistic guys to eat at McDonald's and expect them to make friends with the other diners. But if you bring the community here and offer them something of value, that's how you start to build connections."

That word – "integration" – is a stealth missile these days. It's being used by executives in state and federal governments to champion the rights of autistic people while defunding their programs and housing options. Till recently, clients with Medicaid could live and work together in "intentional communities" for the disabled. Those places, often founded by handfuls of parents as alternatives to group-home placement, looked and felt a lot like Morse's program. They were typically set on farmsteads or gated compounds, gave the residents jobs that also happened to be therapeutic, and allowed them to make the kinds of lasting friendships they'd never formed at home or in school. Over time, the roots they sank there let the parents exhale, confident their kids would be safe and cared for after they passed away.

But in 2014, the central Medicaid office in Baltimore launched a strike on intentional communities. Saying that farms and compounds "segregated" residents from taking part in the world at large, it issued a "final rule" that will effectively cut off funding for communities unless they make massive changes. Parents across the country were shocked and outraged to learn that their housing choices may be quashed. "The government we thought was our partner is now acting like our enemy," says Alison Singer, the co-founder and president of the Autism

Science Foundation, whose daughter is nearing her age-out date. "This is all about money, not 'freedom,'" says Jill Escher, president of the Autism Society San Francisco Bay Area, who has two profoundly disabled children. "They took a look at their budget costs and said, 'To hell with them. Let's cut their spending now.'"

But Morse, through some combination of luck and foresight, fashioned a program exempt from the final rule. None of her 90 adults live in a group. Typically, they share a house with their provider families and one other impaired adult in their age range. Most of the providers have experience working with people with disabilities – special-ed teachers, group-home managers. They genuinely like this population and often earn more looking after them than they did at their day jobs. (The state pays them \$30,000 to \$60,000 a year, per client.) I visited several of these houses and found them warm, beckoning places where the youths seem more like nephews than boarders. They eat dinner with their hosts and join them on family outings. "My guys love dinner theaters," says Donna Cavagnac, a former case manager of a substance-abuse program who now cares for two SLC adults in her home. "If I didn't have them with me, I'd be lonely. They've given me so much more than I give them."

Sitting next to her at a table at the Share Cafe is a hugely thankful mother named Linée Baird. Four years ago, her son, Ryan, moved to SLC from a staff-intensive residential campus. Since the age of nine, when he'd been sent away to school by his heartsick, end-of-their-rope parents, he'd known nothing but the locked-door, vigilant care of the New England Center for Children (NECC), a residential setting for autistic kids with histories of severe behaviors. Over time, Ryan learned to curb his tantrums there – but only around people he knew. "He would lose his mind when someone visited our house – the lamps and tables would start flying," says Baird. "And forget about taking him to the store for a quart of milk – there was no going anywhere with him."

On his 22nd birthday, June 14th, 2012, Ryan moved from the NECC to the Amesbury home of Martha Dowse and her adult son Matthew, a staffer at SLC. Days later, Dowse put in a distress call to Morse. "Ryan was out of control, dragging things out of his room and throwing them – really hard – down the hall," says Dowse, a petite but unsinkable woman who's worked for nearly 30 years with foster-care kids and dementia patients. Morse's staffers showed up quickly, but Ryan raged for hours, breaking his new furniture to bits. Some time before 5 a.m., Hurricane Ryan blew over. That morning, when he woke, the staffers said nothing about the carnage. Bashfully, he helped sweep up the debris.

For months, everyone walked on eggshells around Ryan. He refused to leave the car when staffers drove him to the farms, and he staged other throwing fits, though shorter in length. "I've never given up on a client," says Morse, "and we'd have found an alternative house for Ryan. But Martha refused to quit on him. She said, 'I know this guy can do it; just give me time.'"

A psychiatrist (whose FXS son takes part in the program) switched him to the drug my son is on. Bit by bit, his anxiety eased; his mood shifts were less hair-trigger. And then, without notice, several remarkable things happened. Ryan got out of the car and took a tour of the stables; a month later, he was loading sacks of grain off the truck before the rest of the work crew arrived. He'd always had some language, but now it began to evolve. He began to tell Martha that he loved her and that he'd "be right back" when he left to spend the weekend with his parents.

Fast-forward to the morning when I toured the farm with Morse. Out of the corner of my eye, I saw Ryan go by, carrying a sack of birdseed in his arms. Though the wind was fierce enough to make a snow globe of the sky, he calmly unscrewed the bird-feed tubes and filled them up with

seed. His aide hovered behind him, rocking to keep warm, but Ryan would not be rushed. The birds, said Morse, depend on him to eat.



Clients like Ryan help maintain the Gateway Farm Shared Living Collaborative. The meaningful work helps improve their language and behavior. Megan Hill

Returning to the barn, he stopped and put his hand out. "I'm Ryan," he said, briefly meeting my gaze, then picked up the sack and walked on.

All week long, I met youths like Ryan, which is to say, youths like my son. Boys who'd joined the program with minimal language came over to tell me which rappers they liked. Young women talked about the boys they found cute, and showboated for me on horseback. How had Morse succeeded where others before her failed, releasing these kids from the lockbox of their symptoms to become their bravest selves?

"All those years they're being told what to do: 'Sit still. Match shapes,'" she says. "But when you give them real options and show them that you mean it – well, that's when they find out who they are."

It begins with placing them in homes that feel like sanctums. Morse helps to personalize their bedrooms – colors, fabrics, bedding – to create a womb to retreat to at day's end. She eases the kids into the program slowly: maybe 10 minutes in the barn, then a 20-minute walk to burn off anxiety and start again. Once they're comfortable at the stables, she might add an hour at the cafe, then the studio and the greenhouse, observing closely. "They'll show you pretty quickly what they like to do, though I'll always try to add choices. I'm looking to buy a carwash and maybe a laundromat; those are great sensory jobs that give them face time with the public, but in small doses they can handle." The kids' typical workweek ranges from eight to 25 hours; for that, they're paid the minimum wage, something very few programs do.

Then there's the piece that no other agency offers: a nightlife for these kids and their new friends. Morse hosts them at the Horizon Club, where dozens of young adults come to boogie and mingle, and take their first steps toward dating. There are movie and bowling nights, and

Wednesday and Thursday there are ballroom-dancing classes. Autistic kids terrified of being embraced slowly draw together over weeks and months till they're fine in a ballroom hold. "It normalizes the experience of being touched," says Morse, "and these are kids starved for human contact." The development she's kindled has outstripped her wildest hopes. The program has spawned several long-term couples, including two who've left Shared Living households and taken apartments together. "I've never met a kid, no matter how impaired, who wasn't a social creature," Morse says. "My next task is to figure out how to start them sooner. Why wait till they're 21 to begin their lives?"

It bears saying that Morse's isn't the only game in town when it comes to Shared Living options. Her state has several firms that do some version of the model, including agencies in Boston and Worcester. "We don't have the farming piece, but the rest of it, yes," says Jeff Keilson, senior vice president of Advocates Inc., whose outfit has 50 clients in scattered sites. "There are folks who need a group home and I'm the first to say so, but the guys we've taken out of there are so much happier. They have jobs they like going to, make friends, and have providers they really bond with long-term. The motto we all go by is, 'A life like any other' – and that's what we offer people here."

When its costs are added up, the annual bill for a Shared Living slot comes to about \$80,000, including day-hab. That isn't a small sum, but consider the alternative. For the average group-home bed, Massachusetts spends \$120,000 a year – and considerably more for kids with Ryan's behaviors. Add the cost of day-hab, and the state spends almost double what it pays to firms like Keilson's and Morse's. In 2013, only five percent of Americans with disabilities were living with provider families, but the trend line is going up. In New Mexico, it's 50 percent; in Texas, 25. Morse sees a tomorrow in which Shared Living is the standard provision: "We can't keep building group homes; it'll collapse the economy, and we'll run out of staffers in five years." But the focus also has to be on the factors that make the Massachusetts model so special – nurturing job sites and an avid social life – which forge a way forward for stalled kids. "This is the future," Morse says, "and the future is starting today."

Back at Luke's school, I sit with him again, needing another dose of my son before we part. As we rote-read the text of *Clifford's Family*, I find myself floating off to Morse's farm, picturing this sweet child in her stables. How would she get a kid so addicted to indoor pleasures – his books, his laptop, his woodblock puzzles – to put on a snowsuit and feed the chickens? I can scarcely dream it – but nothing will stop me from making it so. Changing Medicaid rules, drastic program cuts – Elaine and I will fight to the death for the future of our child. He's spent almost 18 years behind locked doors. We owe him no less than a life worth having.

"Kiss!" I say now. "Daddy's got to go." He tilts his head and shoulders in my direction. Though I've got him in a bear hug, I can feel his eyes swivel, looking for his just-fixed Kindle Fire. As I release him, murmuring "love you, love you, love you," he freezes me with a gaze and says, "Home."