

The Architecture of Autism

By Michael Tortorello

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SONOMA, Calif. — Here is a truth about children with autism: they grow up to become adults with autism. Advocates estimate that over the next decade some 500,000 such individuals will come of age in the United States.

No one can say for sure what adulthood will hold for them. To start, where will everyone live and work? A 2008 Easter Seals study found that 79 percent of young adults with autism spectrum disorders continue to reside with their parents. A solid majority of them have never looked for a job.

And yet the life expectancy of people with autism is more or less average. Here is another truth, then, about children with autism: they can't stay at home forever.

This realization — as obvious as it is worrying — has recently stirred the beginnings of a response from researchers, architects and, not least, parents. In 2009, a pair of academics, Kim Steele and Sherry Ahrentzen, collaborated on “Advancing Full Spectrum Housing,” a comprehensive design guideline for housing adults with autism. (An expanded book on the topic is scheduled to come out next year.)

Perhaps the first development to closely follow their template is Sweetwater Spectrum, a residence for 16 adults whose abilities and disabilities span the full range of autism. The innovative \$10.4 million project opened in January in the heart of California wine country, and its founding families and board hope to make Sweetwater a model for like-minded experiments across the country.

“You hear about different organizations planning to do these things,” said Dr. Ahrentzen, a professor in the Shimberg Center for Housing Studies at the University of Florida, in Gainesville. But “it takes time to get all these different funding sources in place.”

Ms. Steele said: “Did it become fashionable? All of a sudden there are a lot more.”

The pair ran off a list of new and prospective housing projects on Cape Cod and in the Catskills, Phoenix and suburban Minnesota. One of the most promising efforts, Dr. Ahrentzen said, is Airmount Woods, in Ramsey, N.J., which will welcome tenants in November.

But it would be hard for any of these campuses to look as “visually stunning as Sweetwater on the outside,” Ms. Steele said, with its 3,250-square-foot, four-bedroom, five-bathroom houses near a picturesque downtown.

It’s easy to plan a pleasant day at Sweetwater. Start off the morning with 30 minutes on the elliptical trainer in the exercise room. For breakfast, how about collecting a few fresh eggs from the chicken coop to cook in the community kitchen? Sow a tray of tomato seeds in the expansive greenhouse, shoot a few baskets on the outdoor hoop. And if it’s Friday, why not drop by activity night in the social hall?

These amenities are central to the enterprise, said Sweetwater's chief executive and executive director, Deirdre Sheerin, 53. The public image of living with autism is one of lethargy and social isolation, she said. Picture someone "sitting on a Barcalounger with a video game, eating weird foods." By contrast, everything about Sweetwater exists to inspire a "life with purpose."

To start, residents have chosen to move here; they have chosen their housemates, too. Similarly, families contract for their own care, be it round-the-clock support or drop-in help. In one sense, Ms. Sheerin said, Sweetwater is a glorified landlord: each tenant signs a 12-month lease and pays rent (\$650) and an association fee (\$2,600) every month.

At the same time, Sweetwater's mission statement lays out some ambitious principles. Residents will be able to age in place. The community should "accommodate a broad financial spectrum," subsidizing residency for a quarter of its tenants. And attendants (who are not Sweetwater employees) should be offered incentives to encourage stable, long-term care relationships.

George Uberti, a 28-year-old personal attendant, likes the idea of helping clients in a community that belongs to them. "But the real difference is the resources," he said. "We have a pool here that's just outside. We have a library. We have a farm. Normally, a big part of supportive living is we have to manage behaviors within certain settings. We have to ride the bus."

Sweetwater, by intention, will be a kind of laboratory to work out ideas that range from the mundane to the profound. Will nontoxic building materials improve the daily experience for a population that often reacts strongly to sensory irritants? Will the residents of a more responsive building require less expensive care?

Perhaps Sweetwater will prove that an oversize kitchen counter can encourage autistic adults to cook and dine together, forming friendships and community. But even that ideal is complicated. As more than one Sweetwater parent has wondered aloud, what does “friendship” or “community” mean to someone with autism?

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HERE IS WHAT it looked like on a Saturday evening at the end of summer, when two dozen residents, families and caregivers gathered outside the rec center for a cookout.

Ashley Pease, 25, was giggling and hopping to the Xbox game “Dance Central.” Her party outfit included a black bridle helmet and a stuffed elephant. (As Mr. Uberti said: “Everybody likes to dance in their own time. But no one knocks it back the way Ashley does.”)

John Edmonston, 25, was drinking a juice box on the floor, although this was hard to see. He had positioned a giant beanbag over his head and trunk to promote a sense of calm.

The mustering of residents was no small accomplishment in itself, Mr. Uberti said. “We tried to do one of these when we first moved in, and it did not go well. We could barely talk the residents into coming into the kitchen.”

Indeed, Ms. Pease’s housemate, Chris Jackson, had shifted from the edge of “Funkytown” to the kitchen, then to the patio, before retreating across the courtyard. He had barely checked in with his mother, Patty Jackson, 54, which worried her not a bit. Chris is hardly the only 22-year-old in America to ignore his mom in public. Plus, she remembered the alternative.

Before moving into Sweetwater, he spent 10 years at a residential school in Boston. Every month, his parents would make a three-day cross-country trek from their home outside San Francisco. Leaving at the end of those visits was wrenching.

As his father, Mark Jackson, 56, recalled the next day: “It was miserable.” His son is nonverbal, and when he is upset, his behaviors can be challenging. He sometimes hits his caregivers; once or twice, he has bitten them. Even so, Mr. Jackson added: “These guys are vulnerable. They can’t really report if they’re unhappy.”

Sweetwater is an open campus, and a host of attendants and parents are watchful all the time. “Now we take him into town for ice cream,” Mr. Jackson said, “kiss him on the cheek and say, ‘I’ll see you next week.’ ”

Ms. Jackson had prepared a bag of snacks for her son and another for Mr. Edmonston, whenever he emerged from his beanbag shelter. “Johnny is gluten-free,” she said. “I brought some gluten-free brownies.”

It was parents who founded Sweetwater, and the place has taken the shape of what Mr. Jackson called “an extended family.” Maris Buesser was interrogating her housemate’s mother about the car she had parked in the lot. (“Does the Mercedes CLK have buttons on the steering wheel?”) Nearby, Ms. Buesser’s mother was trying to arrange a duet between her daughter, who plays flute, and another resident, Christopher Kite, who plays piano. Soon, Ms. Buesser, 23, and Mr. Kite, 28, were discussing Mercedes-Benzes.

Ms. Buesser’s mother, Stephanie Ozer, 57, looked on approvingly. “That may not sound like much,” she said later. “But that type of interaction and back and forth? That is something I’ve dreamed of.”

What needs to be said here is how limited the dreams have been for parents after their autistic children age-out of the school-based support system at 22. Ms. Buesser was lucky to find a new program at Santa Rosa Junior College called College to Career.

But the notion of sending her to a distant group home held no appeal, said her stepfather, David Schoenbach. Ms. Buesser attended Sonoma Valley High School and she performs with the Sonoma Hometown Band. “She knows many more people in town than I do,” said Mr. Schoenbach, 61. “She walks down the street and people say ‘hi’ to her.”

Ms. Ozer, her mother, said, “We would fantasize that maybe with a few families we could get together and buy a house in Sonoma and set up our own supportive-living model.”

But when you are raising a child with autism, she said, the hassle of the moment often distracts from the crisis on the horizon. “I just remember we would lie in bed at night looking up at the ceiling and say, ‘What are we going to do?’ ”

Ms. Buesser, who was listening from across the room, said, “I’m staying here for life, right, boss?” And then she asked, “Are there bats here?”

Her housemates are unfazed by such questions, Mr. Schoenbach said. “They’re definitely her tribe,” he said. “And she recognizes it and is delighted to be around other people with autism.”

As the cookout wound down, Ms. Buesser wondered aloud, “What would a black widow spider do if I touched his eyes?”

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ONE OF THE NEW design goals for supportive living is that the buildings shouldn’t look like supportive living. That said, the project’s lead architect, Marsha Maytum, from the San Francisco firm Leddy Maytum

Stacy Architects, drew extensively from the Steele and Ahrentzen standards. Many of her design decisions were practical ones, like specifying extra-durable, high-impact wall finishes and replaceable carpet tiles.

Also, there is a floor drain in every bathroom. As Ms. Maytum explained, “Water can be a really interesting activity for people with autism.”

Safety and security were other concerns. The kitchens use induction cooktops to limit the possibility of burns. And while the perimeter fence is slotted (Sweetwater is not a fortress against the neighborhood), solid planks span the bottom few feet. Residents are free to walk out the front gate, but it’s probably best that they not treat the fence like a ladder.

A bigger design challenge was to see a house through the eyes of an autistic client. For example, the layout of all four dwellings is identical: a neighbor’s place should feel like home. And multiple seating options encourage an individual to be near the action without necessarily plunging into the fray.

Another way of limiting noise annoyance was to place pairs of bedrooms on opposite sides of the house, instead of in a dormitory-style row. Ms. Maytum had an additional consideration here, too. “What happens when people fall in love as the years go by?” she said. “These private spaces also provide for the possibility for a couple to have their own wing.”

Ultimately, she doesn’t really know which, if any, of these strategies will make a significant difference. And given the newness of autism architecture, neither does anyone else. As Ms. Sheerin, Sweetwater’s executive director, said, “I often liken it to sailing a ship while we’re still building it.”

Returning to the finished site after a few months away, Ms. Maytum expressed an eagerness to see how the residents had started to personalize and occupy their spaces. But at this point, it is still hard to say. For much of the day, Sweetwater can appear almost deserted, like an office park on a Sunday. Most of the residents depart around 8:30 a.m. for school or life-skills training. When they return, they often withdraw to their rooms.

Dr. Ahrentzen, who visited the nearly three-acre site during construction, said: “It’s very spacious for 16 people. If it was half the size, it might not look as void during the daytime.”

More than an acre has been given over to the organic farm, which a solitary staff member, Rachel Kohn Obut, has filled with thriving row crops, a u-pick garden and the beginnings of an orchard. The idea is for the residents to participate in a market operation, perhaps as a vocational opportunity.

Over the summer, however, the farm did not prove a popular destination. “They didn’t seem to like getting their hands dirty,” said Ms. Kohn Obut, 30. “So it’s all gloves, all the time.”

In truth, many of the other common areas have a vacant feeling as well. On Sunday evening, Christopher Kite returned from an overnight visit with his sister, Nicole, to find his home empty. Most of the time, he said, “It’s like I’m in my own 3,250-square-foot house.”

The living room furniture looked as if it had just been delivered. The shelves contained a single book, an early John Cheever novel that no one claimed. Standing in the kitchen, his sister said, “I don’t get the sense that anyone uses this space. I think Chris is the only one who cooks.”

Mr. Kite attends college courses in Santa Rosa and interns a few mornings a week at Ramekins, a local inn and culinary school. And he expresses gratitude for the opportunity to exercise at Sweetwater (he closely tallies his laps and miles), and to establish his independence. Back in the family home, Ms. Kite said, “I felt he had been in a stagnant place for a while.”

But sometimes it seems to Mr. Kite that there are too many hours in the day. “It’s frustrating because I’m capable of having an intelligent conversation with someone,” he said. “And that’s not possible here.”

What about Ms. Buesser, the flute player he had chatted up at the cookout? “She’s pretty much obsessed with brands of cars,” he said. “I can’t get her to talk about anything else.”

At some point, he added, “we’ve covered everything we can about Mercedes CLKs and SLKs, and our opinions differ on those two models.”

The comedy of the situation was not lost on him. “I prefer the SLK convertible,” he said. “And she prefers the CLK. She likes the more expensive Mercedes!”

That feeling of isolation continued into the fall, Ms. Kite said recently over the phone. A few weeks ago, he spent a weekend back home with his mother and decided not to return to Sweetwater.

Sweetwater, it seems, is an experiment not just for the community but for each individual. Mr. Kite still needs to retrieve his furniture.

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SINCE THE FIRST RESIDENT, Chris Jackson, moved in at the start of the year, “literally hundreds of inquiries about Sweetwater Spectrum” have piled up in the office, said Ms. Sheerin, the executive director. More than 30 applications are pending for the remaining three bedrooms.

She also hears weekly from parents hoping to develop their own versions of Sweetwater. Fortunately, one of the group's stated goals is to "create and foster a model that can be replicated nationwide."

Mark Jackson recently started a consulting company to lead others through the process, having guided the building of Sweetwater for several years as an almost full-time volunteer. From that experience, he now tells parents, "It takes three things: time, money and knowledge."

It's that middle item, the cost, that presents the most obvious barrier. Several scholarships aside, families pay \$39,000 a year for a child to live at Sweetwater. That expense, said Ms. Steele, the researcher, "will preclude people who don't have a trust fund or wealthy parents from living there."

Ms. Maytum, the architect, resists the notion that Sweetwater is somehow extravagant. Building anywhere in the vicinity of the Bay Area is expensive: the land alone cost \$1.45 million. "This is standard wood-frame construction," she said. "And that can be done anywhere. You don't need a swimming pool to make this successful."

Or maybe that's exactly what you need. A little before 4 o'clock on Sunday afternoon, Ms. Pease and Mr. Jackson migrated from their shared home to the pool, as they do most warm afternoons. An attendant, D. J. Banta, 21, flung a water polo ball into the middle. Mr. Jackson splashed Ms. Pease, and then Ms. Pease splashed Mr. Jackson, and then Mr. Jackson tossed the ball, and Ms. Pease tossed the ball, and the game went on in this fashion for a good half-hour.

Mr. Banta said, "They don't normally get along — except in the pool."

Ms. Pease skipped the ball onto the pool deck, and Mr. Jackson took the halftime break to plunge below the water. When he surfaced, his expression seemed not just unbothered, but serene.

Mr. Jackson would never say how he perceives the entire experiment that is Sweetwater. But his feelings in the moment were as plain as his face:
Here comes the ball!