

NEWS | BAY AREA

Jewish housing crisis: Aging parents fear for their special-needs kids

BY EMMA GOSS | JANUARY 21, 2022

When Tobie Shapiro goes to bed each night in her Alameda home, she's kept awake by the same thought about her child: "What happens when I'm gone?"

She's referring to her adult son, Meyshe Shapiro-Nygren, 34, who has never been alone and still lives with her. Meyshe has autism, and while highly educated in several languages, skilled at playing the viola and an artist who is able to earn a modest income selling his <u>paintings</u>, he struggles with verbal communication. He requires full-time supervision, which his mother has provided throughout his life.

Mother and son are also observant Jews. They light the Shabbat candles every Friday evening, keep kosher and, prior to the pandemic, would attend weekly services at Netivot Shalom in Berkeley.

Shapiro, 74, is determined to find a suitable Jewish residential community for Meyshe as soon as possible, both because of her age, and because she wants him to establish friendships — maybe even find a girlfriend.

"I am fully aware that my mother cannot care for me forever; it's heartbreaking and terrifying," Meyshe said in an email to J. "Being forced to fend for myself is my greatest personal fear." He says he's seeking a Jewish residential community where he can "converse with neighbors, make friends, find love, and perhaps become a father" but feels "helpless" over finding such a place.

There is a <u>range of private</u>, <u>nonprofit and state-funded housing options</u> for adults with intellectual and developmental disabilities, but for those wanting to live in a Jewish residential environment, the choices are much more limited. The Bay Area has only three such communities, and Shapiro says none of them serve her son's needs.

The three residences have total combined space for just 19 residents. Two facilities are managed by S.F.-based Jewish Family and Children's Services. The third, with space for six residents, is in Campbell, a long drive for Shapiro to make from Alameda.

"From my survey of places, most of them are halfway places, like you're in college, and you need help, and we will help you be independent," Shapiro said, noting that Meyshe needs to be somewhere he can live indefinitely that provides round-the-clock support. "But as far as long-term [and Jewish], where are you going to live? That, there, seems to be a void," she said.

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Ryan Berman is in full agreement. He's the director of disability services at JFCS and acknowledges the Bay Area's lack of affordable long-term Jewish residential communities for adults with special needs.

"The need is great," Berman said.

And it extends well beyond the Bay Area's Jewish community.

The rate of children diagnosed with autism spectrum disorder has been rising steadily since the CDC began tracking ASD in 2000, according to a March 2020 report from the U.S. Centers for Disease Control. In 2016, it had climbed to one in 54 children.

Now, communities across the United States are facing a shortage of housing as the population of autistic children grows into adulthood.

Among the Jewish options, JFCS runs San Francisco's <u>Gary Shupin Independent Living Community</u>, which opened its second S.F. location in Laurel Heights on Jan. 2. Called Gary's Place, it is set up for young men ages 18 to 34 who are taking their first steps living outside of their family's care. The Shupin House has seven rooms for men and women who have some independent living skills already mastered, and who require less support.



Both Gary's Place and Shupin House infuse a Jewish focus into the social programming and activities.

"Somebody recently moved out who was there for nine years and said, alright, I'm ready to take this next step in my independence, and I'm going to get a condo'. And they did," Berman said. "We still provide support to them, but now in their own living space...

They still participate in all of our social club activities, but they took that next step."

Meyshe expects he will always need full-time care. "Complete independence is something for which I feel I do not have the capacity," he wrote in his email, a more comfortable form of communication. "Writing is easier for me than talking, since my mind is like a racehorse, as a teacher once said about me."

"It's very frustrating, and it's scary," Shapiro said of her concern for Meyshe's future well-being.

<u>State-funded regional centers</u> offer lifelong services and support for individuals with intellectual and developmental disabilities and their families. Shapiro says she relies on the <u>Regional Center of the East Bay</u> for most of Meyshe's activities, including his art programs. It's one important reason Shapiro wants Meyshe to stay in the East Bay, to continue receiving services from the center.

"This is all he's ever known. Stability is really important for people on the spectrum," Shapiro said. "Change is very difficult."

Berman said Shapiro isn't alone in feeling as if there isn't a Jewish home that meets her son's needs, and JFCS wants to build one, but it won't happen in the short term.

"We recognize that there are individuals who do need more support than the majority of the clients we currently see," Berman said, and the launch of Gary's Place took priority. "It's 1 million percent on the list."

In the meantime, the next closest full-time Jewish residence that cares for adults with special needs is the one in Campbell. It's called Hatikvah House, and it's the only Jewish group home in California that offers a kosher kitchen. The house opened in 2000, when the property's owners, Len Shustek and his wife, Donna Dubinsky, wealthy Silicon Valley tech entrepreneurs, partnered with Hatikvah Inc. founder Sally Weider, a woman with two special-needs adult children. In 2013, Shustek donated the house to the Addison-Penzak JCC (now part of Jewish Silicon Valley). Hatikvah House residents celebrate the Jewish holidays and enjoy weekly kosher Shabbat dinners.



Meyshe Shapiro-Nygren (left) and Tobie Shapiro at the piano at their home in Alameda. (Photo/Michael Fox)

"It's a little pearl of Jewish values in Silicon Valley that nobody really knows about, because it's a tiny six-bedroom house," said David Hurwitz, president of the Hatikvah House board of directors.

Last spring, the house was on the verge of closing for good, as the longtime administrative director was planning to retire by the end of summer and there wasn't enough part-time staff available to cover every shift. Family members were picking up their loved ones and providing for them on weekends. Despite attempts to recruit a new director and raise the pay, the organization was not able to attract a qualified replacement, Hurwitz said.

In August, the house was purchased by <u>Life Services Alternatives Inc.</u>, a Campbell-based nonprofit organization with 14 other group homes under its umbrella in Santa Clara County.

Hurwitz calls the purchase "a godsend" that will allow Hatikvah House to continue long into the future, with staffing support from LSA Inc.

Hurwitz noted that the Bay Area generally has insufficient housing for adults with special needs. "And then you add on top of that, if you're Jewish, and you need a loving, stable care home — and oh, by the way, it'd be really important that there be a kosher kitchen — now you're really in a pickle," Hurwitz said.

Though not a specifically Jewish solution, there is some hope in the <u>Big Wave Project</u>, a nonprofit and cooperative community for adults with special needs now in development in Half Moon Bay. Parents and caregivers will provide the oversight and quality control at the 57-unit campus, which sits on a farm that residents will learn to tend as a form of employment. In December 2022, Big Wave will welcome its first 37 residents, six of whom are Jewish.



Sam Shenkman driving an electric car in Half Moon Bay.

Sam Shenkman, 20, is one of them. He was born prematurely, weighing just 2 pounds, and as a result lives with developmental disabilities. His father says he loves electric cars, karaoke and watching YouTube videos. He doesn't require a full-time aide but needs assistance with daily tasks such as showering and food preparation. His father, Paul Shenkman, owner of Sam's Chowder House in Half Moon Bay, heads Big Wave's nutrition committee.

"Any sensitivities or allergies will be accommodated," Shenkman said of the food that will be provided to residents. "We can have a chef, and they'll be able to accommodate everyone's special needs," he said, noting that Sam has a gluten and dairy-free diet and eats only organic foods. Accommodating a diet free from pork, shellfish and other unkosher products, that would not mix milk and meat, would be within Big Wave's capabilities, he said.

Another incoming Big Wave Jewish resident is Sam Bowers, 27. He grew up in the East Bay and Judaism has played a central role in his life. He has autism and is mostly, though not entirely, nonverbal. He currently lives with a full-time caregiver in a San Leandro apartment.

His mother, Linda Bowers, 72, is thrilled that her son will be immersed in community with other Jewish residents within Big Wave's social circle. And with parents involved in much of the programming, celebrating the Jewish holidays is "certainly a possibility," according to Big Wave spokesperson Sarah Sherwood.



Sam Bowers will be moving into Big Wave in Half Moon Bay, which has a farm residents will learn to tend.

Still, Linda is frustrated about the Bay Area's limited options for long-term, Jewish-focused residential communities for her son.

"In the Jewish community, there's sort of a paradox," she said. While the Jewish community has responded to the need for Jewish senior living communities, "for people with developmental disabilities, there's no acknowledgment of having some kind of service model."

She and her husband, John, can relate to Shapiro's worries about how long she'll be able to care for her son. They have firsthand experience.

"Sam had been living with us his entire life, and a few years ago, my husband and I got sick at the same time," Linda said. John was diagnosed with non-Hodgkin lymphoma (he's now in remission), and Linda suffered a serious back injury. The Regional Center of the East Bay provided an emergency placement for Sam in a group home in Oakland.

"He was neglected," Linda said of his care at the facility. "And we had a really difficult time. We were told repeatedly that there were no alternatives."

Fortunately, a private caregiver they had started paying out of pocket to support Sam at the group home suggested that the Bowers rent an apartment in his San Leandro complex. Sam moved in, allowing him to continue with the full-time caregiver. It's been a workable solution as Sam waits to move into Big Wave.

Shapiro, meanwhile, feeling frustrated at the lack of options and knowing that time is at a premium, has been working on an idea to start a Jewish residential community in the East Bay for adults with special needs, and she and her son are actively looking for other Jewish families who want to join them.

"I can't do that all alone," Shapiro said. "Where are the people that would want to be involved in this area, who belong to the Regional Center, who have their programs set up, whose parents want to be involved and want to be close by, and aren't going to pick up and move someplace else?"

For her part, should the Jewish residential community come to fruition, Shapiro is ready to jump in. "I will be the den mother, I will do the cooking," she said. "I'd love to."



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