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HEADLINE: After Closing, Some Sweet Success; Md. Officials, Families Say Former Great Oaks Residents Are Doing 'Remarkably Well'

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BODY:

After more than 20 years of being jostled awake on someone else's schedule, of rising to the cacophonous noises, barren walls and stagnant air of a state institution, Beth Simms finally enjoys this commonplace luxury: She can sleep in on Saturday mornings.

In the Annapolis cottage where she now lives, in a room decorated with a pink and green Laura Ashley comforter and a dried flower arrangement, Simms can stay in bed late on weekends, and no one bothers her. Other experiences finally are part of the routine of life, too, with none more ordinary than the walks she loves to take through nearby Quiet Waters park. The squirrels that scurry across the bike trail there are a real delight.

Such small details are what count as the sweetest successes for Simms and the other men and women who last spring were forced to leave Maryland's Great Oaks Center. Nearly 140 were part of the exodus, but the people left until the end were considered the most difficult cases, usually profoundly retarded individuals with complex medical or behavioral conditions. Their families adamantly opposed their ouster and, despite sometimes chilling allegations of deficient care, they bitterly fought the sprawling facility's closing.

But prodded by a federal lawsuit by a disability rights group, Maryland officials ultimately refused to back down. In fact, they decided that virtually everyone leaving Great Oaks would be placed in neighborhood group homes, not state institutions. Virtually everyone, they declared, could make it in the community.

A year later -- a sometimes wrenching, difficult year later -- they believe they were correct.

"People are doing remarkably well," says Georges Benjamin, Maryland's deputy secretary for public health services. "We did the right thing."

The stories supporting that conclusion are both major and minor, and the narrators are the families themselves. Salvatore Marvaso, of Wheaton, talks about his 33-year-old daughter Carol, who now lives in a group home in Laurel. The staff has gotten the hang of feeding her through a tube into her stomach and, according to Marvaso, she regularly takes weekend outings and goes to the swimming pool.

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"Everything is falling into line," he said last week. "She seems more comfortable in her environment. She seems to like everyone. You can tell by her expression."

Virginia Massa's father says he feels much the same. That's the only reason he consented recently to take a vacation out west, the first time in decades he'd been more than a day's drive from Virginia, 53. She also lives in Laurel, in a one-story house with a spacious eat-in kitchen and a comfortable family room with a brick fireplace, a recliner and a plaid sofa and love seat. The van parked out front takes her to doctor appointments, and a nurse arrives every afternoon to administer medications.

And with all the individual attention and conversation focused on her, Virginia is even beginning to say a few words again, about 35 years after encephalitis damaged her brain and destroyed her promising life.

"She's doing real fine right now," said William Massa, of Rockville. "We're fortunate to have a couple of very good people taking care of her."

Some are less sanguine. They have watched staff come and go several times over. They say promises for therapies or certain specialists remain unkept. They worry about how the state can fully monitor thousands of individual sites. There have been several injuries of note -- one man had four fingers broken in a still unexplained accident -- and six deaths during the year. The frequent insinuation is that those might not have happened at Great Oaks.

A few families have had rocky transitions.

Malcolm Jack lost 14 pounds from his 6-foot-1 frame, and when the scale hit 121 pounds, Marie Jack and her husband became alarmed. "They fed him like he was some girl trying to diet," his mother recounted. He was given lots of salads, "and they're not one of his favorite things to begin with. He's a meat and potatoes person."

She feels better now that her 38-year-old son has regained some of that weight, and she concedes that at his Laurel condo he often looks cleaner than he did at Great Oaks: "He gets haircuts more often. He doesn't seem to have any bruises. But he doesn't seem as happy."

Not far below the surface is her lingering sense of loss over the permanence and stability that the institution -- Malcolm's address since he was 16 -- symbolized to parents. Its bricks and mortar represented an implicit promise that their children always would be sheltered. Even with injuries and abuse, many saw it as safer than the unknown.

"I still worry about Malcolm," said Marie Jack, of Bowie. "But then, I probably always will, no matter where he is."

The Great Oaks diaspora was not the first in Maryland, nor will it likely be the last. The state still has four large facilities in which about 650 people live, and although officials insist they have no immediate plans for closures, their philosophy and funding have swung sharply away from institutional care. In the \$ 343 million budget proposed for the Developmental Disability Administration in fiscal 1998, community services programs -- both residential and day programs -- receive \$ 279 million, up from \$ 249 million only two years ago.

Whether that's enough, however, remains the issue at the heart of the Great Oaks debate, just as it remains the crux of a continuing national discussion. In the last 20 years, the number of mentally retarded people living in institutions in this country has dropped from 150,000 to 60,000. Many parents have contended that community programs to serve those with the most severe problems are inadequate and inadequately funded. They've complained of poorly trained staff and constant turnover, and some say increased deaths are the result.

In California, where one study found significantly higher mortality rates in the community than in institutions, community advocates are criticizing the state's efforts to transfer 2,200 people to group homes in five years.

The local situation has not always given families confidence. In a deposition taken two years ago in the case

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brought by the Maryland Disability Law Center, one state administrator testified that one-third of community programs here had serious problems. Although officials maintain that major strides have been made, the parents of former Great Oaks residents say much more should be done. It's one of the few points on which they and the institution's opponents agree.

"The case was never about just closing Great Oaks and moving people into community programs," said Elizabeth Jones, executive director of the Maryland Disability Law Center. "It was about realigning the system. The state has to create a system that's as visible and as strong as people thought Great Oaks was, and that's a far more difficult task."

The task is complicated further by the long lists of families waiting for state services. Maryland officials say about 500 of them are considered in critical need of placement in a residential program. Diane K. Ebberts, director of the Developmental Disabilities Administration, is well aware of the challenge of those numbers.

"We very much have both the obligation and the intention of making sure all people in our system receive all the support they need," she said. "Yet that goal raises crucial public policy questions. Decisions are going to have to be made whether these services are entitlements. How much are the taxpayers of Maryland willing to pay?"

Doubtless, more money will be required, and even more expansion of existing programs. Finding and retaining qualified staff already is difficult. Because of the state's reimbursement rates, workers in many group homes earn less than \$ 7 an hour for jobs that can be demanding and draining.

For nearly a decade, lawmakers have defeated legislation to raise those wages. A cost-of-living adjustment was vetoed by Gov. Parris N. Glendening (D) two years ago, just as community agencies were starting to prepare for the frenzied proliferation of services that would be required by closing Great Oaks. And with cuts probable in the federal Medicaid funds that help support these programs, agencies aren't necessarily hopeful about the future.

"Sometimes you can earn more at McDonald's," said Diane Hutto, executive director of the Maryland Association of Community Services.

The front gate to Great Oaks, on the border of Montgomery and Prince George's counties, is locked these days, and the cottages and wards that housed thousands of people for a quarter-century are vacant. The buildings are scheduled to be razed and will be replaced by a private 1,800-unit residential complex for seniors.

Kathy Hargett drives by the Capital Beltway exit for Great Oaks as she heads east from Rockville to visit her daughter, Beth Simms. She is pleased with the changes she's seen since Simms moved to her small, light-filled cottage at Langton Green. The 34-year-old woman has a worker assigned to her every day, and her mother thinks it has helped her focus her often unpredictable behavior. "She's gotten calmer," Hargett said.

Last week Hargett took a shopping bag of summer clothes for Simms to try on. The late afternoon visit was uneventful. The two sat together on the sofa, hands interlaced, Hargett smoothing Simms's dark hair and laughing about the absence of gray.

It was a perfectly wonderful, normal moment.

GRAPHIC: Photo, carol guzy; Photo, dayna smith, Former Great Oaks resident Carol Marvaso, with residential counselor Asata Sarnor, now lives in a group home. Kathy Hargett with daughter Beth Simms in the house where Simms moved after Great Oaks closed.

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