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Contents

['FOOD, FILTH, OR FLOWERS'](#)
[UNDAMMING THE MAINSTREAM](#)
[LIMITED RESOURCES](#)
[LESSONS LEARNED](#)

Section: STUDENTS

Students *with* mental retardation are knocking on college doors, and colleges are responding

Dateline: PORTLAND, ME.

NOEL P. THOMPSON loves his life at the University of Southern Maine. He studies entrepreneurial marketing, has a paid internship helping a local bank *with* its clerical work and event planning, and eagerly gives his time to a campus service organization that runs a summer camp for terminally ill children. He savors the friendships he has made here, and his occasional pang of homesickness are assuaged by the satisfaction he derives from *learning* to live on his own.

"I like to be independent," he says.

His *carpe academiam* attitude would be admirable in any college student. But Mr. Thompson is not just any student: He was born *with* Down syndrome, a chromosomal disorder that has impeded his *intellectual* development. He got to the university through a combination of his own herculean efforts and the help of Strive University, a fledgling program designed to provide a two-year postsecondary *education* experience to students *with developmental disabilities*.

He says the program has given him the confidence to consider going into advertising or becoming a disc jockey. In the meantime he is interested in sitting in on some daunting classes. "I want to study physics," he says, "because I haven't done it before."

Mr. Thompson, 24, is one of six young *people*, all *with* Down syndrome, who last fall were the first to enroll in Strive University, which was established by the University of Southern Maine and a South Portland-based nonprofit organization, Strive, that serves young adults *with disabilities*.

The program is part of a recent surge in the number of postsecondary opportunities for *people with* mental retardation. In response to growing demand, dozens of colleges have established similar programs in the past few years, and others are considering doing so, even though the efforts tend to be costly and have not previously been thought of as part of most colleges' missions.

The National Down Syndrome Society is working *with* public and private colleges in New Jersey to create

a model system for providing postsecondary **education** services to 18-to-25-year-olds **with** mental retardation. "There is a huge interest in this," says Madeleine C. Will, director of the society's national policy center. "It is a reflection of a tremendous increase in expectations on the part of families regarding their children **with intellectual disabilities**, and I think it is a reflection of the progress that we have made in special **education**."

The U.S. Department of **Education** is encouraging the proliferation of the programs and financing the development of a national database on those available (<http://www.thinkcollege.net>). The organization assembling the database, the Institute for Community Inclusion at the University of Massachusetts at Boston, has identified more than 50 such programs so far.

Some college administrators in charge of **disability** services question whether **people with** mental retardation have the **intellectual** capacity to earn associate or bachelor's degrees, even **with** extensive support services and several extra years of effort. Most administrators resist the idea of altering courses and their requirements to accommodate **people with intellectual disabilities**.

Advocates for such programs acknowledge the limitations of **people with** mental retardation. But, noting that colleges are filled **with** students who have unrealistic academic or career expectations, they say it is better to let those **with** mental retardation experience failure than to prevent them from aspiring to **higher** goals.

People with intellectual disabilities "want something more than what typically has been available," says Stephanie Smith Lee, who is director of the **Education** Department's office of special-**education** programs and has a daughter **with** Down syndrome. "They have bigger dreams."

'FOOD, FILTH, OR FLOWERS'

Only a small fraction of adults **with** mental retardation have access to college. Most receive educational services through their public school systems until they are 21. Their employment options generally are limited to sheltered workshops or low-wage, menial jobs; many become fast-food workers, janitors, or landscapers. "In our field we call it 'food, filth, or flowers.' It is relegating an individual to a life of poverty," says Debra Hart, coordinator of school and community projects at the Institute for Community Inclusion.

Like many parents of **people with** Down syndrome, Irene Mailhot, of Lewiston, Me., worries about her child's future. She has devoted much of her life to helping her daughter, Christina, overcome her **disability**. She has provided Christina **with** years of physical, occupational, and speech therapy, and has fought hard to have her mainstreamed into regular classrooms from the time she entered preschool.

Ms. Mailhot's efforts seemed to pay off when Christina received a high-school diploma -- but her graduation meant that she was no longer eligible for her school's educational services. "Christina would so many times say, 'I wish I could go to college,'" her mother says. "She loves to learn, and she has missed it ever since high school stopped."

Irene Mailhot watched in distress as Christina became miserable in a grocery-bagging job. A single parent, Ms. Mailhot worried that after she died Christina would be unable to support herself.

Hoping to find her daughter a more stimulating job, she contacted the University of Southern Maine last year. She was relieved to learn about Strive University. And she was ecstatic when the program, which evaluates applicants' high-school transcripts and letters of recommendation, accepted Christina as one of 6 successful candidates from a pool of 65.

At Strive University, Christina shares an apartment **with** another student in the program and a resident adviser, who teaches her how to do things like cook and pay her bills. She takes a special class designed to help her adjust to campus life, and is auditing a German course to learn the native language of her mother, an immigrant.

Christina, 25, says she hopes to have a career as an advocate for **people with disabilities**. "I think that not many **people** know this," she says, "but we have brains, too, and we are as normal as they are, and they need to accept that."

Irvin N. Shapell, a publisher of books on children **with developmental disabilities**, had motives similar to Irene Mailhot's when he became involved in setting up Strive University and enrolled his 21-year-old son, Jake. "I want Jake to have the same kind of life as his siblings," Mr. Shapell said when interviewed last fall. "I would like Jake to have a job and the kinds of rewards that are important to him. I want him to

live in the community. I want him to have real neighbors, just like you and me."

Jake died unexpectedly of endocarditis, an inflammation of the heart, in December. Although Mr. Shapell has taken leave from his job to mourn, he continues to help oversee Strive University as a member of its planning board. Other colleges have a duty to set up similar programs, he argues: "Colleges ought to acknowledge that they have never given these **people** a chance, and they ought to give them a chance."

UNDAMMING THE MAINSTREAM

The first campus-based programs for **people with** mental retardation arose in the 1970s, in response to widespread efforts to close the institutions where many had been housed and integrate them into society. For the next two decades, most of the programs served adults of all ages, placed little emphasis on academics, and segregated their participants from other students for most of the day.

The programs emphasized vocational training and helped those who had been institutionalized adjust to life on the outside, says Debra A. Neubert, who has studied the evolution of such programs as an associate professor of special **education** at the University of Maryland at College Park.

The federal law that kicked off the mainstreaming movement in elementary and secondary schools, the **Education** of All Handicapped Children Act of 1975, phased in a requirement that local public school systems provide services to children **with** cognitive **disabilities** until they graduate from high school or reach the age of 22. In the 1990s, public school systems began working **with** colleges to establish campus-based programs for 18-to-21-year-olds who had not completed high school, out of a belief that such students are best served in an age-appropriate setting.

"They don't want to stay in high schools for seven years taking the same curriculum from the same teachers, sitting next to 14-year-olds," says Meg Grigal, who examined several such programs as a research associate at Maryland. "Twenty-one-year-olds in a high school are not socially valued," she says. "You put that 21-year-old on a college campus, and suddenly you have a different lens through which that student is being viewed."

Most of the campus-based efforts to serve students **with** mental retardation are still based on that model, in part because it is the only one that state agencies and local school systems are legally required to finance. Although the participants often have access to college facilities and sometimes are free to audit college courses, by definition they remain high-school students.

By contrast, many of the newest programs put the emphasis on college.

A few offer the chance to earn college credits. Among them is the two-semester Single Step Childcare Program, on the Dundalk campus of the Community College of Baltimore County. Established three years ago, it offers **people with** cognitive **disabilities** the modified courses and closely supervised internship experiences they need to qualify for state certification as child-care workers.

Melissa E. Silverman, of Owings Mills, Md., is one of two **people with** Down syndrome who graduated from the program in 2003. She now works as an aide at a child-development center near her home. While she only makes about \$6 an hour, she enjoys working **with** children. "Her child-care certification opened the door for her," says her mother, Janice A. Silverman.

Other programs seek to provide some semblance of a college experience to students who have graduated from high school or, at least, reached college age.

Taft College's Transition to Independent Living Program, established in 1995, was one of the first to offer dormitory living. Although it helps **people with** an array of cognitive **disabilities**, most of the 39 students enrolled have some form of mental retardation.

Jeff Ross, director of student-support services at Taft, a two-year public institution in California, says **people with** mental retardation have for decades been quietly revealing the need for such programs by signing up for classes at the state's community colleges. They gain admission through open-enrollment policies, and tend to quickly get into academic trouble for want of adequate support, he says.

Taft's program has a four-year waiting list of applicants who have qualified for admission, and has fielded queries from about 200 other **people** who want in, Mr. Ross says.

In a few cases, **people with** mental retardation have been going on to college and earning credits

without enrolling in special programs. Among them is Katherine Apostolides, a 21-year-old from Pittsburgh who enrolled at Becker College, in Massachusetts, last fall.

Although Ms. Apostolides was born **with** a severe form of Down syndrome, her parents insisted that she be mainstreamed in school. They also read books on raising gifted children and treated her like one. "My friends and relatives all thought we were crazy. They thought we were in denial," says her mother, Paulette P. Apostolides.

Katherine earned a diploma from her local high school, where she wrote for the student newspaper and was a cheerleader. She was determined to enroll in a college as a regular student, but her parents spent years finding an institution willing to accommodate her.

At Becker she receives a range of support services, including the help of a mentor -- a resident adviser in her dormitory -- hired by her family to work **with** her 10 hours a week. She has had some trouble making friends in college and she dropped a class in medical terminology that demanded a great deal of memorization. Yet she has earned several academic credits and has made substantial progress, her mother says.

Elaine M. Lapomardo, Becker's vice president for enrollment management, says Katherine is the college's first student **with** mental retardation: "She inspires us."

LIMITED RESOURCES

Many colleges regard their programs for **people with** mental retardation as a means to provide work experience and, in some cases, financial support to students in special **education**, psychology, and related fields. Such is the case at George Mason University, which charges the 18 students enrolled in its transition program for young adults **with intellectual disabilities** an annual tuition of \$15,000 -- more than twice what it charges its other students -- and uses part of the revenue raised to pay the graduate assistants involved.

Colleges see their participation in such programs as strictly voluntary. Unlike public schools, they are not required by federal law to undertake such efforts, and the Americans **With Disabilities** Act generally has not been interpreted by college administrators as obliging them to alter their admissions policies, academic standards, or instructional practices to serve **people with** mental retardation.

Especially given rising enrollments and tight state budgets, most public four-year colleges "are having a hard enough time educating the students that they have right now," says James Kessler, president of the Association on **Higher Education and Disability** and director of the department of **disability** services at the University of North Carolina at Chapel Hill. He admires the Strive University program in Maine, he says, but adds, "I don't think we can replicate that program here, and I don't know many campuses that can replicate that."

Caroline B. Forsberg, director of **disability** services and information for the State University of New York, says she is skeptical about how much students **with** mental retardation actually learn when they take regular college classes **with** the help of intensive support services. "The aides end up doing the stuff," she argues. The students, she says, "don't do much of the work, and they really don't get the experience that the parents think they are getting."

In agreeing to help sponsor Strive University, the University of Southern Maine stipulated that its faculty members would not change their courses or course requirements to accommodate students in the program, who are allowed to take regular classes, but not for credit. The Strive organization handles admissions and covers nearly all of the university's costs, paying Southern Maine \$57,000 annually for tuition, fees, and much of the cost of services.

This year Strive University charges each of its students about \$11,800 for tuition, room, and board. It has raised \$600,000 -- half from donors and half through matching grants from state and federal sources -- to help cover its operating expenses over the next two years. The program is well on its way to raising an additional \$1.7-million to pay for its student housing, a brief bus ride from the campus.

It employs four resident advisers, two support staffers, a student-life coordinator, and a coordinator of **education** and training, and it plans to hire more **people** next year, when it takes in six more students. A local employment agency agreed to help find internships for those enrolled.

Peter Brown, director of Strive University, says one of its goals is to teach its participants to live independently enough to need just \$5,000 a year worth of state services, as opposed to about \$45,000

for most adults **with developmental disabilities**.

Southern Maine's Muskie School of Public Service is monitoring Strive University's performance. "This is not a haphazard foray," says the university's president, Richard L. Pattenaude. "It is a worthwhile risk because it is a good idea."

LESSONS LEARNED

It's Thursday morning, and the Strive University students have assembled for a twice-weekly class that teaches them how to navigate college life so that they will get the most out of their two years here -- and will feel comfortable taking classes elsewhere when they are done.

The class begins **with** an open- mike session. Most of the students read aloud short poems that they have written. Jeff R. Goranites, 22, delights his peers by standing up and impersonating his idol Elvis Presley, complete **with** shimmying hips and an air guitar.

Afterward the students discuss how they felt while speaking in public. They move on to a lesson on how to make written schedules, so that they will not miss class.

They have encountered a few bumps in their transition to college. Christina Mailhot was deeply hurt one day when a student on campus called her "retard." Her mother says she would like to see the student-conduct code revised to more clearly prohibit such slurs.

Paula L. Thompson, Noel Thompson's mother, says her son has had difficulty getting a volunteer position at the campus radio station. But she is hesitant to complain, she says, because she does not want to hurt the relationship between Strive and the university.

For the most part, however, the students are enjoying themselves. Each is taking at least one regular course this semester, in subjects including Chinese, music, and psychology.

Susan M. Campbell, who as executive director of advising and academic resources at Southern Maine oversees its involvement in Strive University, says it is difficult to predict how far the students will go academically because "the range of ability is huge."

"What we know," she says, "is that there is an awful lot of enthusiasm and excitement and motivation. And oftentimes that is 90 percent of the battle, isn't it?"

PHOTO (COLOR): Jeff R. Goranites does his Elvis impersonation at a meeting of Strive U. classmates at the U. of Southern Maine.

PHOTO (COLOR): Nathan Doucette, Noel P. Thompson Christina Mailhot, and Julie Jermann take a class at Southern Maine on how to navigate college.

PHOTO (COLOR): Nathan Doucette and Jeff R. Goranites take a Portland, Me., city bus to the campus.

PHOTO (COLOR): Jeff. R. Goranites works out on a treadmill in the Southern Maine gymnasium before class.

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By Peter Schmidt

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