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Down syndrome barriers falling

College opportunities expand for disabled

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By anyone's measure, Bridget Brown has had a successful high school career. At Hinsdale Central, she was on the speech team, snagged roles in two plays and never missed a dance.

Now, like so many of her peers, she is focused on continuing her education. But unlike them, she was born with Down syndrome.

"I love to learn and I don't want to stop," said Brown, 19, who graduated last spring and still proudly wears her letter jacket. "That's why people go on to college."

In the past, the educational road for students like Brown came to an abrupt halt after high school. But in recent years, young adults with developmental disabilities are finding a burst of opportunities--from Maine to Elmhurst--that once would have been unthinkable.

What sets these programs apart is the focus on academics and campus life. While the curriculum may be modified and practical skills--resumes and job interviewing, for example--are usually part of the mix, the choices are far more challenging than the menial labor and sheltered workshops of an earlier era.

"This population is desperate for better," said Cynthia Johnson, director of a program at Washington state's Bellevue Community College, which offers an associate's degree to students with Down syndrome or other cognitive impairments.

Johnson compared the inequities to "the colored schools of the 1950s," when African-American children were put in separate classes and not expected to learn. "This is a civil rights issue and a moral issue," she said. "Its time has come."

Just a year ago, only 35 programs existed for these students. Now there are more than 90 at two- and four-year colleges, according to the U.S. Department of Education, including one at Elmhurst College, which began in September and is touted as the first of its kind in Illinois.

Each program is different. Though the courses are demanding, they are taught differently. Less "chalk and talk," more hands-on experiences and technology, such as voice-activated computers.

"This isn't some watered-down curriculum," Johnson said. "We push our students somewhere between frustrating and challenging ... that's where true learning happens."

In addition to scholastics, some of the programs are residential and include cooking and money-management skills, while others are geared to commuters. Most students receive certificates. Some programs promise a standard degree; all offer a hefty dose of self-esteem.

Critics fear goals too high

But a handful of experts fear that the new academic emphasis is setting students up for failure.

The major factor driving the change: The Individuals with Disabilities Education Act of 1975, the federal law that became known as "mainstreaming" in K-12 schools. And "No Child Left Behind"--President Bush's sweeping educational reforms that hold districts accountable for the performance of all students--only strengthened the mandate.

Research shows that students with developmental disabilities--those who in the past were called mentally retarded--are more likely to hold a job, have friends and live independently if they get into a post-secondary program.

But a more typical scenario has been a world of low-wage employment, such as fast-food or custodial jobs. For parents who have advocated for their disabled children since preschool, that's unacceptable.

"This is a unique experiment that is coming from the bottom up," said Troy Justesen of the U.S. Department of Education.

Family donates \$250,000

Steve Riggio and his wife felt so strongly about continuing academics for their 17-year-old daughter born with Down syndrome that they recently donated \$250,000 to develop post-secondary models at two New Jersey colleges. They hope the programs will be replicated nationally. "It's the next frontier," Riggio said.

The availability of programs after high school was like "going from a cruise ship to a dinghy," he said. "My daughter had the benefit of a wonderfully inclusive educational environment," said Riggio, chief executive officer of Barnes & Noble Inc. "Why should that end?"

The program at Elmhurst College, called Elmhurst Life Skills Academy or ELSA, allows disabled students to get a four-year academic experience with all the social trappings of campus life. The customized curriculum is sprinkled with everything from literature to life-skills courses.

The program's 11 students pay regular tuition rates of about \$20,000 a year but will receive a certificate with a transcript instead of a diploma at commencement.

They're as likely to participate in theater, the bowling team or multicultural club as any other undergraduate. But unlike other students, fewer than 10 percent of students with developmental disabilities go on to college.

"The hard, stark ugly reality is that current statistics equal unemployment, poverty and isolation," said Madeline Will of the National Down Syndrome Society.

Bridget Brown's prospects are brighter. The Darien resident is currently transitioning from high school in an early childhood education program at the Technology Center of DuPage, where she takes some math classes and is enrolled in the child development program. Her strengths, she says, include being helpful and a good public speaker. For the last five years, she has run her own Individualized Education Plan meeting--the blueprint for a student's classes and services.

"I am really good at advocating for myself," she said with a broad smile. "Hopefully, the rest of my life will be as fun and exciting as high school."

Last month, she toured Elmhurst College. To Brown, attending the ELSA program would be her dream.

She is not afraid to "ask for help when I need it and try new things.... I'd even try living in the dorm if I could do it with a friend."

Student living his dream

ELSA freshman Patrick Hartmann already is living his dream. Not only is the River Forest resident attending a four-year school--where his course load includes math, science, technology and English--but the picturesque suburban campus reminds him of the East Coast school where his twin brother is enrolled.

"It looks similar and the people are the same," said Hartmann, 21, who was born with spina bifida and wants to work with computers. "I like being able to be in a four-year college."

Hartmann yearned to continue his education after graduating from Oak Park and River Forest High School, but his options were limited.

After trying several local schools, where both helpful instructors and a social network were elusive, he has found his niche at Elmhurst. There, he has plenty of assistance and has a group of friends who regularly trade barbs in the school cafeteria.

ELSA coordinator Nancy Cheeseman would like to see the program go to another level, with on-campus housing similar to the University of Southern Maine and George Mason University. "Our goal is to offer as much of a college experience as possible," said Cheeseman, who has been fielding calls from excited parents all over the country.

But some critics question the usefulness of degree-granting programs, saying they saddle disabled students with unrealistic expectations and provide them with skills that don't necessarily lead to employment or independent living.

"A degree is not a life. A degree is an accumulation of academic credits, but other parts of the person need to be considered," said Carol Burns, director of the PACE program, a course for disabled students at National-Lewis University in Evanston. "The opposition would say that's not inclusion."

The debate has reached Justesen, head of special education for the Department of Education, who takes umbrage at critics who say such programs are setting up students for a fall. He points out that plenty of young adults enter college with improbable hopes and struggle to find a job after graduation.

"When a [non-disabled] 13-year-old boy says he wants to be a football player or a rock star, no one says 'Oh you can't do that. Oh, it's not realistic,'" Justesen said. "What's wrong with allowing children with intellectual disabilities to experiment with what they want to be?"

The federal government isn't promoting these new programs, "but we're watching it," he said. "It's definitely at the leading edge."

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