LUMINA FOUNDATION

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Learning without limits

Campus-based programs empower students with developmental disabilities

INSIDE

On the cover: Daniel Castellanos, an award-winning prep cook in Lancaster, Pennsylvania, displays his detail-oriented salad-making prowess. Castellanos is a 2016 graduate of Millersville University — the first student in the university's Integrated Studies program, which is designed to serve students with intellectual disabilities.

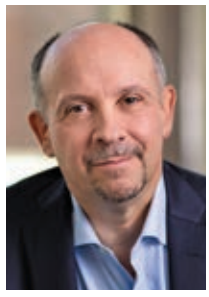
Editor's note: The stories in this issue of Focus were reported and written by Bob Caylor, a journalist with more than 30 years of experience at newspapers in Minnesota, Ohio, and Indiana. At the News-Sentinel in Fort Wayne, Indiana, he was an award-winning columnist and editorial writer and reported extensively on business and environmental issues. He is now a writer and photographer for Easterseals Arc of Northeast Indiana, as well as a freelance journalist and book editor.

PRESIDENT'S MESSAGE

Part of the value of higher education, beyond applicable knowledge and a degree, is exposure to new ways of thinking. Learning to collaborate with people of varied viewpoints is a lifelong skill, and diverse thinking leads to novel ideas and solutions.

But to achieve true diversity in thinking and learning beyond high school, students with developmental disabilities must also be included.

For years, such students have faced barriers to success. K-12 special education often segregated them in separate classes and classrooms, preparing them for employment in a limited range of jobs or in "sheltered workshops," doing piecework for low wages. As for college, it often seemed unthinkable for people with intellectual disabilities, and students on the autism spectrum who were admitted usually had to make their way on their own as best they could.



This harms not only those with disabilities, but also students in the mainstream, who are denied the chance to grow and learn by interacting with others. It also harms society at large, by essentially sidelining a segment of the population that can — and should — contribute to our collective well-being.

In short, students with disabilities must be part of building a better future — which means they need and deserve high-quality education beyond high school.

Fortunately, the nation's colleges and universities are beginning to get the message. Institutions around the country are offering programs that promote full integration, allowing students with developmental and intellectual disabilities to get the specialized support they need, while interacting with the campus community and being genuinely challenged in their work.

This issue of Focus will examine that trend, highlighting three programs that empower students with developmental disabilities. For instance:

- You'll learn about Utah State University's Aggies Elevated program. Founded after a group of parents raised funds to get it started, the two-year program serves about 15 students at a time. These students take courses for college credit, receive mentorship and tutoring, and participate in a required internship that helps them find jobs. The program teaches valuable life and social skills, whether through homework help and tutoring at the program's "Home Base," or during shopping trips to purchase supplies for weekly get-togethers.
- You'll read about the Integrated Studies program at Millersville University in Pennsylvania, a program that weaves students with intellectual disabilities fully into the college experience. Students get the support they need while fully immersing themselves in college life through integrated classrooms, dorm life, and clubs. Daniel Castellanos, the first student in the program and a 2016 graduate, used his Integrated Studies experience to find rewarding employment — and to prepare for an even brighter future. Castellanos, now an award-winning prep cook at a popular restaurant in Lancaster, plans someday to open a dinner theater.
- You'll also learn about Western Kentucky University's Kelly Autism Program, which supports students on the autism spectrum through mentorship and focus on both interpersonal and social skills. Even as classes are held remotely because of the COVID-19 pandemic, the students still get support, including graduate student David Merdian, who is completing a master's degree in economics even while in semi-isolation.

The three programs featured here — like many of the nation's nearly 300 programs for students with intellectual disabilities and 70 programs for those with autism spectrum disorder — help students earn credentials and find meaningful jobs. And they do that while fostering the social skills and connections that any student needs to thrive.

In other words, they do what all good post-high school programs do: They prepare students for successful careers — and lives — in our diverse democracy.

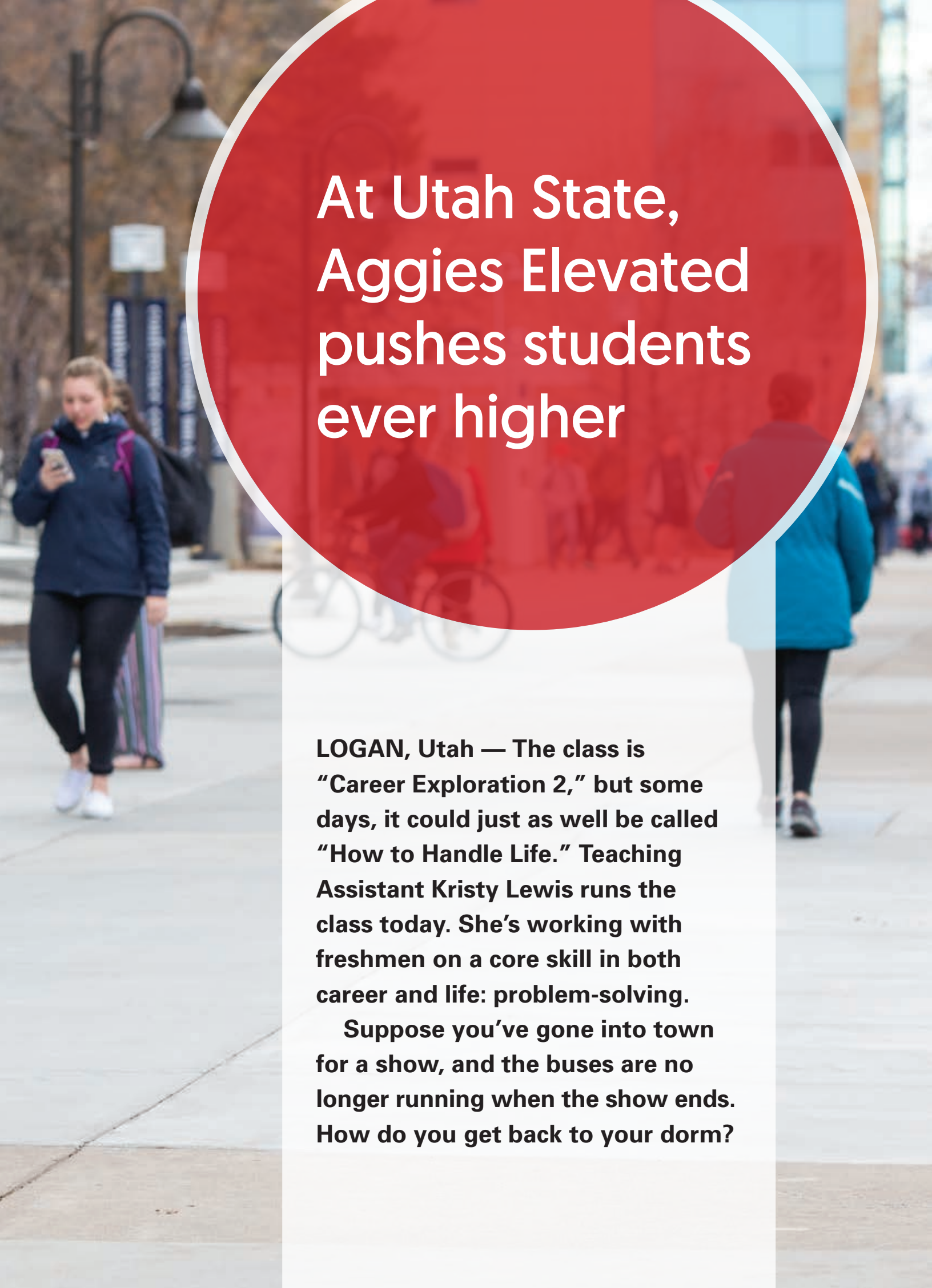
In addition to the material in this printed version of Focus, there's a wealth of information on Lumina's website, www.luminafoundation.org. There, Focus offers several extra features and a number of links to other programs and advocacy organizations.

All of the material in this issue of Focus is designed to serve the foundation's commitment to foster social equity. My Lumina colleagues and I are committed to that cause, not just in education, but in American society at large.

We believe strongly that the higher education system must work better for ***all*** students, including those with developmental disabilities. And we're convinced that the programs featured here have important lessons to teach.

Jamie P. Merisotis
President and CEO
Lumina Foundation

Bret Giebel (left) and Willy Wilson met in the fall of 2019 as students in Utah State University's Aggies Elevated program, which was launched in 2014. Now the two are fast friends — and sometimes-snarky roommates.



At Utah State, Aggies Elevated pushes students ever higher

LOGAN, Utah — The class is "Career Exploration 2," but some days, it could just as well be called "How to Handle Life." Teaching Assistant Kristy Lewis runs the class today. She's working with freshmen on a core skill in both career and life: problem-solving.

Suppose you've gone into town for a show, and the buses are no longer running when the show ends. How do you get back to your dorm?

"Walking is an option," she suggests, but it's a long way, and it's late. You could take a cab or an Uber ride, if you have the money. But that's not for everyone, either. Lewis acknowledges that she's never used Uber and has ridden in a taxi only a couple of times.

Jake Ortiz suggests, "How about you ask someone?"

Another student weighs in. "That is NOT the best plan," he said.

"You are right!" Lewis says. "You don't want to just go out there and thumb it."

"You can never be too careful," says Willy Wilson. Rides is the subject, and Wilson spots an opening to tease Bret Giebel, who sits beside him. On a recent ride to Wilson's home in Park City, Utah, Wilson learned that "all his music is out of date. The Beach Boys!"

"What's wrong with the Beach Boys?" Giebel asks.

Wilson and Giebel met last semester. Now they're roommates — and best friends. They love "hammocking" outside their dorm and playing "sting pong," a high-impact contact variant on table tennis that includes whacking the opponent in the back with a ball after every point. After years of not quite fitting into mainstream classes in high school, they're completely at home on the campus of Utah State University.

The reason they're on campus is Aggies Elevated, which began in 2014 after a group of parents helped raise money to create a program that opens college education to students with intellectual disabilities. It's a two-year program designed to help students land competitive employment after they graduate. The term "competitive" specifically excludes the old model of employment for people with intellectual disabilities: a "sheltered workshop" offering lower wages and limited expectations.

Sue Reeves, who now directs the program, designed promotional material for its initial fundraising when she worked in another department at Utah State. She attended the opening fundraising event in October 2013.

Inspiring a career change

"I listened to the faculty members talking about what keeps them up at night, these young adults with intellectual disabilities sitting at home on their parents' couches, playing video games because they can't go to school, they can't get a job, they can't whatever. I totally drank the Kool-Aid," she remembers. It inspired her to shift her own career from communications to rehabilitation counseling — working with people who have intellectual

Defining intellectual and developmental disabilities

The term "developmental disabilities" encompasses a wide range of physical and mental disabilities. According to the Centers for Disease Control and Prevention, parents report some sort of developmental disability in one of six children. Intellectual disability and autism spectrum disorder both are considered developmental disabilities.

About 2% of U.S. residents have intellectual disabilities, which impede their cognitive functioning and their ability to master life skills. People with intellectual disability may have difficulty with reading, writing, math, communication, social skills, or other activities of daily life. Intelligence Quotient (IQ) measurements are controversial because IQ scores have often pigeonholed people in ways that constrain their opportunities and curtail their education. Nevertheless, those scores are often used in diagnosing intellectual disabilities. Scores of 50-70 are often termed mild intellectual disability. Most students who qualify for college programs for people with intellectual disabilities generally have IQ scores ranging from 50-75. A thorough introduction to intellectual disabilities is available at **https://www.parentcenterhub.org/intellectual**. Families looking for college programs for students with intellectual disabilities can find a detailed list of programs and other resources at **www.thinkcollege.net**.

About two of 100 people, more often males than females, have autism spectrum disorder. It affects how people understand and socialize with others, often causing difficulty in interacting and communicating. Many people on the autism spectrum have average or high IQ scores; about a third of people with intellectual disabilities also have autism spectrum disorder. To learn more about autism, **https://www.cdc.gov/ncbddd/autism/facts.html** is a good start. Families looking for college programs for students on the spectrum can find resources at **collegeautismspectrum.com**.

The causes of most developmental disabilities are unclear. Genetics, parental health and behavior, infection during pregnancy, exposure to harmful material (lead, for example) during pregnancy, and premature birth appear to contribute to many developmental disabilities. Three conditions with well-established causes are:

- Down syndrome occurs in people with an extra copy of a chromosome in their genetic code. Mild to moderate intellectual disability is common among people who have Down syndrome. It affects about one in 1,200 people in the United States. More information is available at **www.down-syndrome.org**.
- Mutations in a single gene cause Fragile X syndrome, which causes mild to moderate intellectual disability in most males and in about a third of females. The incidence of Fragile X is estimated at one in 2,500-4,000 males and one in 7,000-8,000 females. Much more about Fragile X is at **fragilex.org**.
- Maternal alcohol use causes Fetal Alcohol Spectrum Disorders, which can include intellectual disability. A recent CDC study found such disorders in three out of 10,000 children ages 7-9. Basic information about FASD is available at **www.cdc.gov/ncbddd/fasd/index.html**. Much more about prevention and support can be found at **www.nofas.org**.

Sue Reeves, who directs the Aggies Elevated program, talks with student Jake Ortiz about an assignment in his Career Exploration 2 class. Reeves says one of the biggest hurdles her students face is what she calls the public's widespread "presumption of incompetence" among students with developmental disabilities.

disabilities. She earned her master's degree in rehabilitation counseling at the same time the first Aggies Elevated class graduated.

The staff-intensive program typically admits just eight to 10 students each year, so that it serves about 15 students at a time. As of a few weeks after the 2019 class graduated, 93 percent of its graduates had found jobs.

The Utah State program is far from unique. Think College, a national center for information on college programs for people with intellectual disabilities, reports that more than 290 schools have such programs. Every state except Wyoming and West Virginia has at least one. Some have many: New York has 33, Florida 21, and Massachusetts 19.

One unusual feature of the Utah State program is that students take courses for college credit. At many schools, students with intellectual disabilities audit their courses. Reeves says in Aggies Elevated, the presumption is students take courses for credit; if they encounter too much difficulty in a course, auditing or pass/fail is an option. Earning college credits provides a foundation that some students use to build degrees.

"Our students leave with about 45 credits if they've taken everything for credit," she said. "We have two graduates who have completed their associate degrees. One is continuing on with her bachelor's, and we have another student who's working on her associate."

Those college credits put graduate Jenna Mosher, 24, on course for two degrees. In 2018, she earned an associate in general studies. In December, she expects to complete a bachelor's degree in integrated studies, with a concentration in human development and family studies.

"I really just want to help people and help kids," Mosher said. "I like elementary school kids and, like, preteen. … So I really want to work with them, whether that's being a teacher's aide, or being a social worker of some kind, or working with the Boys and Girls Club."

Another element of the program — a required internship — ignited her interest in the work. She spent a year working in an after-school program at a nearby elementary school. She helped tutor second-graders and accompanied them during snack times, play, and other activities organized by the staff.

Second-year student Lucy Urquhart (left) works with her mentor, Breanna Anderson, in the 1,000-square-foot space that Aggies Elevated students call their Home Base. Urquhart, 21, was on the verge of graduation when the pandemic hit, upending her plans and sending her back home to Salt Lake City.

Aggies Elevated alumna Jenna Mosher, 24, earned an associate degree from Utah State in 2018 and is on her way to a second degree: a bachelor's in integrated studies. After graduation, Mosher hopes to work as a teacher's aide or social worker. "I really just want to help people and help kids," she says.

She gives Aggies Elevated great credit for her successes. A fundamental benefit: The program taught her "how to feel comfortable that you have a disability." The staff "made the transition for me so smooth, and they accepted me, and they were incredibly supportive. I can't put into words how much they helped me adjust to the college experience," she said.

The fact that she accepts who she is shows in the way she describes her own disability. "I'm very high-functioning," she said, but "I have a lot of trouble with math and remembering large amounts of information." She benefits from the work of note-takers, and she's allowed more time to complete tests, among other accommodations.

She has taken to speaking in schools and on panels to encourage students with intellectual disabilities to recognize their own potential. A key step is moving past the resentment of their disabilities. "You wish you didn't have it. You think your life would be better if you didn't have it. I've gone through a lot of these stages," she says. "But the fact is, you ***do*** have it, and you have that support from your family and friends, and you have that support from your professors and other people in your life."

A malignant misconception

Many obstacles still keep people with intellectual disabilities from considering college. Perhaps the largest is what Reeves calls the "presumption of incompetence," the assumption that college — let alone taking college classes for credit — lies beyond the reach of people with intellectual disabilities. And it's clearly a widespread assumption, since only about 5% of colleges offer such programs. But the 13 students who were in Aggies Elevated this spring aren't confined by low expectations.

Staff members and mentors encourage and support students, but they don't pamper them. Students are expected to meet requirements for classes, and none of the course material is watered down. For many students, doing the course work for general college classes can be a steep climb.

They get help from tutors and are afforded accommodations, such as note-takers, based on their disabilities. Reeves' program offers students still more help, through two classes each semester designed for them (but open to any student), and mentors. Those 10 mentors work one on one with students several times each week. Each mentor works with one or two students.

One such mentor has an especially relevant qualification: She's a graduate of the program. Aubrie Hansen, 27, finished an associate of science degree that she began at a community college in her home state of Wyoming. She intends to continue her education to become a veterinary technician or perhaps a veterinarian.

"Aggies Elevated just pushed goals and said, 'You need to have a long-term goal, but then also have short-term goals that you can achieve,'" Hansen recalled. "You need to take little steps at a time instead of trying to take it in one big chunk."

Now Hansen is the mentor for Giebel, the student

Amy DeBruler (far right), assistant director of the program, conducts a second-year Aggies Elevated class called Navigating Adulthood. Gathered around the table (clockwise, from DeBruler's left) are teaching assistant and mentor Anna Berger and students Lucy Urquhart, Jonny Peay, Trevor Larsen, John Rohman, Derek Krebs, and Sadie Anderson.


Tools
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Crucial
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who so enjoys the Beach Boys and hammocking in his off-hours. As part of her work, Hansen meets with him four days each week, for a total of seven hours. She works with him on course material, and she also helps him plan how to use his time well.

Their sessions continued through Zoom videoconferencing after the spread of COVID-19 closed classes in person. Giebel's mother, Jennifer Giebel, credits Hansen as a major influence in her son's success.

Hansen "holds him accountable each day and each week as he reports to her on his progress. Bret is a 'people pleaser,' and he just beams every time his mentor praises his efforts, his accomplishments, and every time he meets his goals," Jennifer Giebel said. "His mentor helps him learn how to plan, organize, and prioritize his homework. She is a great cheerleader in his corner, and her incredible support helps Bret be successful."

A supportive hub: Home Base

When classes were still in session on campus, those meetings usually took place in Home Base, a room of about 1,000 square feet in one of the newer buildings on campus. It includes a quiet-study room, a staff office, a few computers along one wall, and study tables for students and mentors. Besides the mentor-student meetings, students attend mandatory study meetings there — four hours a week for Giebel — and weekly meetings with Reeves and other staff members.

Home Base is the program's main site for homework help. But there's more to it. Students gravitate there to hang out between classes. Students often work on assignments there outside of mentor and study-group meetings. It's the natural spot for movie nights and parties. It's not just a study hall; it's the hub of a tight community

Aubrie Hansen, 27, (left) is an alumna of Aggies Elevated who earned an associate degree and now serves as a program mentor. Here she works with student Jessica Otty during a study session in the group's on-campus hub, the Home Base.

Mentor Emmy Moore (left) works with Courtney Jorgensen during a one-on-one study session. Structured mentorship is an important feature of the program. There are 10 mentors in Aggies Elevated, each of whom works with just one or two students, meeting several times a week.

within the larger community of the university.

It's a place where all of the goals that students work on — social development, academics, and life skills — entwine. One week, it falls to students Giebel, Wilson, and Lucy Urquhart to organize a party for their fellow students and staff. Mentors Hansen and Lindsay Thunell join in and drive the crew to a Walmart near campus.

Five people circling a single shopping cart make for traffic jams in almost every aisle, but the group makes its way through a quirky list: mini marshmallows, cotton balls, plastic straws, Skittles, facial tissues, Oreos, and more.

They want pingpong balls for one game, plastic cups for another. Wilson finds a prepackaged "Party Pong" kit, apparently for a time-honored drinking game. He asks, "Party Pong, anyone?" raising his eyebrows. He puts it back before mentors Thunell and Hansen have a chance to chide him.

Even in this shopping gaggle, there are lessons to teach. This trip isn't on a university expense account. The three students and two mentors are paying for it themselves, as most people do when they invite friends to a party.

"We try to keep it as low-cost as possible," Thunell explains. "Mostly it's just us chipping in for it." That gives them a stake in figuring out the cost-per-ball of different packages of pingpong or plastic golf balls. Thunell leads this field trip to Walmart, and she prompts the students to read the packages and prices.

The Aggies Elevated class at Utah State includes (front row, from left): Jessica Otty, Kyle Perdue, Willy Wilson, Lucy Urquhart, and Sadie Anderson. (Middle row, from left): Courtney Jorgensen, mentor Hannah Evans, Jonny Peay, mentor Emmy Moore, and Sue Reeves, the program's director. (Back row, from left): Mentor Lindsay Thunell, Bret Giebel, Jake Ortiz, and mentors Aubrie Hansen, Breanna Anderson, and Kaitlyn Wilcox.

Inset top: (From left) Aubrie Hansen, Willy Wilson, Lindsay Thunell, Bret Giebel, and Lucy Urquhart leave Walmart with their carefully chosen items.
Inset middle: Much to the amusement of Ashley Jensen (far left) and Jessica Otty, Kyle Perdue tries to maneuver an Oreo down to his mouth during one of the group's "minute to win it" games.
Inset bottom: Jake Ortiz, Courtney Jorgensen, and Willy Wilson compete in a breath-powered marshmallow-moving contest.

As the shopping contingent fans out around shelves of Oreos, Thunell tells the students, "We need at least 20 Oreos. How would you find that out?"

Urquhart pulls out a big package of Oreos and points out that it contains 20 servings. Thunell turns the package over and directs Urquhart to the nutrition facts label. That shows that a serving of Oreos is two cookies, so there are 40 Oreos in the package. Sold!

The party later that afternoon is a fast-paced sequence of games — a race to lift Skittles out of a bowl with suction through a straw; a contest to see who can pull tissues out of a box one-handed the fastest; a peculiar test of dexterity in which, without using their hands, students try to maneuver Oreos from their foreheads to their mouths. What the games have in common is license to be silly, to laugh, to be social. All the students, in various combinations, take turns planning social events for their peers.

There's a fee to participate in Aggies Elevated: $5,000 per year. For students who pay in-state tuition, the total cost, including room and board, is about $20,000 per year.

Securing internships is a central goal for second-year students such as Trevor Larsen. His internship in the Utah Assistive Technology Program allows him to work with 3-D printing, and he enjoys it.

The AT program began as a service for the repair, lending, and exchange of wheelchairs. Working on wheelchairs — sometimes in tasks as simple as changing batteries — is still a large part of Larsen's work. But he also helps fabricate assistive technology, using the 3-D

printer that turns digital renderings into plastic components for devices ranging from prosthetic limbs to lightweight wheelchairs with frames made of PVC pipe. A recent example: The AT program made a bright purple grid that snaps into place over the screen of an iPad. It was designed for a person whose lack of fine-motor control makes it hard to touch one icon on a screen without sliding onto others. The grid creates a raised square around each icon, making the computer easier to use.

The prototype required some tweaking, and that's where Larsen came in. Using design software, he did some of the fine-tuning, such as changing the size of the clips that attach the grid to the iPad.

"It is the hardest," Larsen says of his work with the 3-D printer. "But it is my favorite."

Exploring the world of work

Internships aren't the only route for students to find jobs or begin careers, but the work experience required in the program sometimes exposes students to work they might not otherwise do.

Roommates Wilson and Giebel both had jobs before they came to Utah State. Wilson loves the part-time sales and rental work he does at a ski outfitter in Park City. Giebel worked for a time unloading donation bins at Deseret Industries, a Church of Jesus Christ of Latter-day Saints version of Goodwill Industries. That job convinced him he would prefer to work outdoors, he said.

The week before the spread of coronavirus ended in-person classes at Utah State, Wilson and Giebel were

(Foreground, from far left): Derek Krebs, Jonny Peay, John Rohman, and Trevor Larsen have their required weekly roommates meeting under the supervision of mentors (background, from left): Breanna Anderson, Ashley Jensen, and Hanna Evans.

getting ready for job-shadowing at the Aggie Recreation Center, a fitness facility on campus. That same week, Lucy Urquhart, 21, near the end of her second year and graduation, had drawn up a list of 30 businesses where she could apply for work when she returned home to Salt Lake City this summer.

But Urquhart's plans are as upended as everything else in this pandemic era. For her internship, she worked this year as an usher in a theater on campus. After an opportunity to visit the set of the television show "Andi Mack" in 2018, working in that field became something between dream and goal for her. So she thought of two jobs, a more ordinary job and a "once-in-lifetime" job.

"Maybe the main job would be in a theater, and then the second one would be being a crew member for TV show and movie sets," Urquhart said.

After the shift to online work in March, Urquhart found the transition jarring, because her time in college was almost over, and suddenly she was uprooted from her roommates and instructors and friends. "At the beginning it was rough, but some days I'm OK, and then some days, I'm still thinking about it. It's on and off," she said. But she still got help from program staff, mentors, and others. Even the instructor in a yoga class has adapted to distance learning, telling students to practice at home and keep a log of what they do and send it to her.

Reeves, the Aggies Elevated director, said distance learning was improvised on the fly, but seemed to work well. Mentors stuck with their intensive consultation schedules. With many parents observing stay-at-home orders, some students had extra supervision in their studies.

"I think parents are nudging them a little bit more to get things done, so we're actually seeing an increase in grades that I think is probably because they don't have all the distractions of all the cool stuff that there is on campus," Reeves said.

Plans for the future already are being reshaped. This summer, as every summer, the incoming class has an orientation week. This year it will include work on distance learning, Reeves said, so students will be prepared if a resurgence of COVID-19 closes campus again.

In any case, Reeves will continue to pursue what she sees as her mission: dismantling the overly protective prejudices that often pigeonhole people with intellectual disabilities into food service, janitorial, or landscaping work — "food, filth and flowers," as she puts it. And at Utah State, her students will earn real college credits as they find their way.

"We know they can do it, and that's kind of a paradigm shift in this field," she said. ●

Aggies Elevated Director Sue Reeves works with Willy Wilson (left) and Jake Ortiz during one of the group's gatherings in the Home Base. Reeves' first exposure to the program was as a communications professional, designing materials to aid in fundraising. Inspired, she made a career change from communications to rehabilitation counseling.

Securing internships is a central goal for Aggies Elevated students in their second year. Trevor Larsen (right) is a good example. His internship with the Utah Assistive Technology Program introduced him to the fascinating field of 3-D printing — and to lab technician Brandon Griffin, here reviewing an example of Larsen's work.

Pennsylvania program aims for full integration – and employment

MILLERSVILLE, Pa. — The kale Caesar salad is a hit at The Pressroom in nearby Lancaster. Daniel Castellanos, a prep cook at the restaurant, says the secret's in the dressing. He describes it, speaking deliberately but not slowly, clipping off each word briskly, never running two words together.

"All you need is lemon juice, some palm oil that you'll find at any convenience store or supermarket," he said.

Daniel Castellanos shows off his signature salad outside The Pressroom restaurant in Lancaster, Pennsylvania. Castellanos is the first-ever graduate of the Integrated Studies program at nearby Millersville University. The program seeks to knit students who have intellectual disabilities into the campus experience as fully as possible.


THE PRESSROOM
THE PRESS ROOM
RESTAURANT • BAR

"You also need eggs, Dijon mustard, Worcestershire sauce, and some anchovies. … With the Caesar dressing I make from scratch, it has a lot of flavors, and it has a lot of textures, something you'll never see in different restaurants."

Concentration on detail helped Castellanos win the 2019 "Restaurant Employee of the Year" title from the Pennsylvania Restaurant & Lodging Association. It's part of the reason that an employee of his modest rank is a star at The Pressroom.

He's also a star at Millersville University, a few miles south of Lancaster. That's where he graduated in 2016, where he gave a commencement address, and where he was the first student in a new program, now called Integrated Studies. Its aim is to bring students with intellectual disabilities to school and weave them into campus as fully as any student.

It is decidedly not "special ed goes to college," as Integrated Studies Director Jan Bechtel puts it. In fact, Integrated Studies is the antithesis of old-fashioned K-12 special ed, with its separate classrooms, special classes, and sheltered-workshop simulations. The goal is uncompromising integration into college life.

The 25 Integrated Studies students live with roommates who aren't part of the program. No classes are designed exclusively for them. They join clubs on campus, but they do not constitute their own club. No social events are designed solely for them. They need to work longer and harder than typical students to learn and understand. But college life, with all its pleasures, challenges, and opportunities, is now within their reach.

Millersville's program isn't unique in seeing new possibilities for students with intellectual disabilities. This public university in southeastern Pennsylvania is among more than 290 colleges and universities in the nation that now offer such programs, according to Think College, an organization based at the University of Massachusetts in Boston. Most programs are small. Only about 5,000 students are enrolled nationwide, and no program has more than 100 students. The average program is smaller than Millersville's.

These programs promote one accomplishment above all others: helping students land jobs — real jobs in the general marketplace for labor, not doing piecework in a sheltered workshop. Millersville's Integrated Studies reports that 100 percent of its graduates have found work.

Director Jan Bechtel

This program wouldn't run without campus champions, and no one champions the cause of inclusion for students with disabilities more than Bechtel. She directs the program, but she doesn't confine her attention to the young people in Integrated Studies. As she rolls around campus in a motorized wheelchair, she can't often travel 200 yards without being interrupted. Passersby stop to confer about students or to tell Bechtel how her recent advice about them has panned out. Some people stop just to give her a hug.

Masked to minimize the spread of the coronavirus, Castellanos shops for fresh produce at Lancaster's Central Market. Someday, he says, he hopes to open a dinner theater — while continuing his work as what he calls "a radical advocate" for people with intellectual disabilities.

Bechtel seems to know everyone. Wheeling through a crosswalk, she calls out a greeting to a uniformed campus police officer who manages traffic at one of the school's busiest intersections. "That's Officer Mike," she explains as she moves toward a classroom building. "He goes above and beyond the call." Later Officer Mike (actual name: Phoulideth Chanthongthip) shrugs off her praise when he hears about it. "I don't do that much," he says.

Bechtel disagrees. "He's always watching out for students. He's a student himself, and sometimes he'll approach them in plainclothes, and he'll ask them how they're doing, if everything's OK."

On her way through a residence hall, she's surprised not to find Vicky, a housekeeping staffer, at work. "She's been here since I was an undergrad," which is to say, 1983. "She's all-around good people." Like Officer Mike, Vicky knows Bechtel, and she also looks out for students. Sometimes Vicky calls Bechtel, just to alert her that one of her students seemed a little down that day and might be struggling.

"Everybody has my cell number," Bechtel said. "Sometimes they call me at home — late at night if need be."

Thomas Neuville, faculty advisor to Integrated Studies and the man who did the most to establish the program, recalls how Bechtel's grassroots network paid off for a particular student. The student took to dawdling on his way to math class — a class he was happy to avoid — by talking with a campus groundskeeper. The worker asked Bechtel about it, and she successfully steered the overly sociable student back to his math class.

This network of watchful staff that Bechtel cultivates doesn't exist just because its members are sociable. Those people play an important part in helping Integrated Studies students move from their cloistered high school settings into much more independent lives.

"There are students who come to Millersville (with) such an impoverishment of experiences — never having relationships, never having friendships," she said. Showing them the range of choices they can make for themselves takes a few years — and a lot of help.

Deltilyn Bonal

Twenty-six-year-old Deltilyn Bonal has difficulty articulating some sounds, and her speech can be difficult for a new acquaintance to understand. But her excitement has a way of overpowering her hesitation.

The best icebreaker is to ask about her photographs. Many of her favorites are as close as her phone. She's quick to stage a show. She swipes through a gallery of studio portraits of three of her friends who volunteered to be her models. They were all savvy to striking just the

Deltilyn "Dee" Bonal, 26, a fourth-year student in the Integrated Studies program, participates in one of the many videoconference sessions that defined her student experience after the pandemic forced Millersville to close its campus in March. She hopes to return to campus for a fifth year in the fall.

Bonal is shown here with her father, D-Otis Bonal, who bought her her first camera when she was in middle school. The gift sparked what may be a lifelong passion. "When I saw how the picture looked, I fell in love with photography," Bonal recalls.

looks they wanted, made up and dressed up, longtime veterans of the selfie era. Bonal slides on, showing photos of a casually dressed redhead with long hair in tight waves. This friend shows more anxiety than she has freckles in her face. "She didn't know how to pose," Bonal said, smiling.

She moves on through images from the first basketball game she shot; she's particularly fond of an action portrait of Millersville men's basketball head coach Casey Stitzel, a big man with a shaved head, who watches the action with penetrating concentration. And there's more: Multiple-exposure shots bleeding one scene into another. Beach sunsets filtered through software that paints them in colors of exaggerated intensity. A friend silhouetted against one of those sunsets as she leaps into the air. Sometimes she signs her favorite shots. When she does, it's not as *Dee*, the way she's often known around campus, but as *Deltilyn*.

No one has come as far as Bonal to join Integrated Studies. She was born in Liberia, near the end of one civil war and just before the start of a second. Several hundred thousand people died in the civil wars that began in 1989 and ended in 2003. Her family didn't wait around to see whether lasting peace would come. Instead, her mother emigrated to the United States.

"She came here to get a better opportunity for life and to get away from war," Bonal said of her mother. Her father followed, while Bonal, her older sister and an aunt ran for cover in Ghana, a few hundred miles away. She didn't make it to the United States until 2003, at age 9.

Her father bought Bonal her first camera when she was in middle school. "When I saw how the picture looked, I fell in love with photography," she recalled. When she needed a better camera for photography class, he bought her a used Nikon D400.

For Bonal, as for all students in Integrated Studies, getting ready for real work — paid employment in a competitive market — is a key objective. Bonal, who

would like to return for a fifth year at Millersville next fall, definitely wants to work, but isn't sure what kind of job she'd like. In the spring, she had an internship in the student affairs office on campus. There she designed flyers to advertise campus events and ran errands for office staff.

One February morning, she set out from the office to the campus police department, about a half-mile away. It was a 10- or 12-minute walk into a brisk headwind. She grumbled about the hike — "Why does it have to be so far away?" — as she bent her head into the wind and picked up her pace. She collected a stack of reports on parking tickets to take back to the student affairs office. Walking back with a tailwind came easier, and she pointed out a building she likes a lot — the former library, now the university president's office. She talks about the campus as familiarly, as fondly, as people talk about their homes and families.

"I'd love to get a job here!" she exclaims.

Prices and revenue sources

For Pennsylvania residents, tuition and fees for 12 credit hours each semester totaled $10,600 for the 2019-20 academic year at Millersville. Room and board was $11,988. Integrated Studies students paid an additional $10,730 in program costs. Yes, the cost of being in the program was higher than tuition for a 24-credit class load, but that fee provides an exceptional level of personal help for each student.

Neuville explained that the program fee covers 13 hours a week of individual help from academic coaches who provide intensive tutoring and mentoring.

Admittedly, $33,000 a year is a lot to attend a public university, but Integrated Studies has many sources of revenue to help fund the program and to help students pay for school. Some include:

- The same federal grants and financial aid available to any college student.

Forced to stay at home because of the coronavirus threat, Bonal works to keep her photo skills sharp by using her father as a model. She came to the United States in 2003, at age 9, after the Bonal family fled the waves of violence that wracked their home country of Liberia during the 1990s.

- State funding for adults with intellectual disabilities.
- Support from area school districts to aid students' transitions to more independent adulthood.
- Vocational Rehabilitation money for job training.
- Medicaid waiver funds, which sometimes cover the cost of intensive tutoring.

Eric Raymond

Few people work with the unbreakable focus that Eric Raymond brings to his internship at the campus career center. There's no idle chatter, no social-media browsing, no meandering. The career center, formally called Experiential Learning and Career Management, runs seminars and workshops to help students evaluate their interests, abilities, and career opportunities.

Raymond's role is managing the supplies that workshop leaders need to perform their work. He consults a calendar of coming workshops, and, one by one, he stocks the necessary supplies. He gathers, collates, and counts stacks of handouts students will need. He packs a rolling suitcase with everything a presenter needs to carry off a successful workshop or meeting: Printed material. Markers. Poster-sized notepads to hang on the wall and capture notes during meetings.

"I like it," Raymond says of his job. "The people here are really nice. I like the fact that I get to move around a lot. I don't like sitting for a lot of time."

Patty Taggart, who runs the career office, has noticed how closely he concentrates on his work. "He is exceptional at that," she said. "He's more focused and gets more done in the time allotted than most of the students here. He's very task-oriented."

And he's learned well on the job. Taggart noted that when he assembled his first stacks of handouts, they were more piles than stacks. It wasn't natural for him to even out the long side of a stack, then the short side, tapping them again and again against a tabletop to even up the sides.

Taggart remembers asking Bechtel how she should work with Raymond on points as simple as properly stacking documents or folding a tablecloth neatly.

"Jan told me, 'Patty, you need to hold him to the same standard as everyone else,'" Taggart remembered.

Bechtel's direction follows the central principle of Integrated Studies: Students need and deserve to take the main thoroughfares of society, not stay in gently traveled, guardrail-protected lanes of their own.

Faculty reactions vary

C. Onek Adyanga, an associate professor of history, welcomes Integrated Studies students to his classes.

"First they come in a little shy," he said. "That could be a function of the background that they're coming from in the high school. … I don't know whether during high school they were isolated from the mainstream student body."

Integrated Studies student Eric Raymond, here attending a videoconference class during the campus closure, also has an internship — a key part of the program's employment-oriented structure. As an intern with the campus career center, Raymond's role is to plan for and provide the supplies that career center staff use to conduct workshops.

But he finds they adjust to his class well. "After a while, I find that they literally just meld in the student body. And they're talkative, very assertive."

All sorts of students come to his class, and he works to create an inclusive atmosphere. "You set a pace that everyone's welcome. Everybody will respect everybody. There's nothing like wrong or stupid answers. Every answer is an attempt, and that attempt might need to be revised," he said.

Melissa Gehret, a biology instructor, has had to work a bit to adapt tests for Integrated Studies students. That adaptation has entailed some trial and error, but she's settled on giving open-book tests. They're a better measure of how well the students are learning to learn, she said, and they help foster organizational skills.

"My goal isn't to see what (they) can regurgitate and supply back to me. My goal is to see: 'Are they organized enough that if they were given information, they could look it up, they could use their notes, they'd learn how to use resources?' So that's my goal, especially if we're going to mainstream them in the job world," she said.

One problem Gehret sometimes encounters is that not all Integrated Studies students have aides to help them, or they have aides who are unfamiliar with equipment used in her introductory biology class. She teaches 144 in her lecture, and she also runs two lab sections of 24 students each. That means she has very little time for one-on-one work with any student.

Integrated Studies student Kelsey Borror (far right) enjoys some unexpected down time on an April evening at the family home in southeastern Pennsylvania. With her around the firepit are (from far left): her stepfather, Dave Warner; brother Kyle Borror; mother Lori Warner, and her much-loved dog, Big Shadow.

Kelsey Borror

When junior Kelsey Borror, 24, arrived at Millersville University, she wanted to be a veterinary technician. "That's what I always wanted to do when I was younger. I never saw myself wanting to work with people because I'm not that social," she said.

That changed when she enrolled in Kathleen Walsh's social work class.

"I took a social (work) class, and it changed my mind on things," she said. "I find it interesting, and I want to help people."

Walsh "kind of persuaded me. … She was like, 'I might persuade you to become this major.' And she did," Borror said.

Since then, she's delved deeply into the topic. Spring semester, for example, she took Social Work Welfare and Law, Human Diversity, and another class on the psychology of racism. How that might turn into a career, she's not sure. Borror finds criminal justice fascinating, so she thinks something on the fringe of criminal justice, perhaps working with kids affected by crime, might be possible.

Just the fact that she sees lots of possibilities for her future is a change in itself. Before she came to Millersville, Borror spent two years taking two classes a semester at a community college. Her mother, Lori Warner, remembers those four semesters as a struggle for everyone. "I felt like I finished another degree myself," Warner recalled. "Millersville has been wonderful for her."

She said her daughter is much more self-reliant at Millersville than she's ever been. Her growing skill in navigating the world pays off directly for Warner. A key example: Her daughter now takes the train, saving Warner two round trips to enable Borror to visit home.

"I seem to be more confident with myself than I was when I got here," Borror said. "When I got here, I didn't really believe in myself that I could do what I can. I didn't think I was smart enough."

In fact, Borror is confident enough to objectively describe her disability. "It takes me longer to understand something for a subject. … It just takes me longer to process it, basically."

In at least one respect, she's already achieved the most important thing the Integrated Studies program strives to instill in students: She works, not as an intern, but as a paid employee. She is a server with a catering service on campus. When at home, she works as a hostess and greeter in a hotel, and before that, as a greeter in a Sam's Club.

Pandemic effects

On March 12 — the day after the NBA canceled its season — Millersville University announced it would close its campus and shift all instruction to distance learning. Borror was stressed at first because she had found online classes difficult, her mother said. But she rebounded well when classes actually resumed at the end of March.

"I can't say enough about Jan Bechtel and what she has the students do and how she goes about motivating them," Warner said. "She's coming up with stuff that I don't even know where she's getting it from. … like a social hour and Jeopardy game online that the kids can do through Zoom."

Eric Raymond has at least this consolation prize: Days before the coronavirus closed campus, he was able to perform onstage at the school as one of "Twelve Angry Jurors." He's loved theater for years. Listening to songs from musicals such as "Hamilton" to "The Sound of Music" is one of his favorite pastimes.

As for the school work, he was comfortable with it. "I took online classes before, so I knew how it goes," he said, adding that the academic coaches with Integrated Studies help a lot. In fact, he thinks he probably did better with school work while stuck at home.

"I think it's easier that I'm home; that way, I can get more accomplished. At school, I feel like I'm not staying as focused," he said. At the same time, he admitted his disappointment over missing the enjoyable work and activities on campus.

Borror, a junior at Millersville who is considering a career in social work, says she's gained a great deal from the program. "I seem to be more confident with myself than I was when I got here," she said. "When I got here, I didn't really believe in myself."

While at home, Eric Raymond visits the historic Newtown Theatre, which bills itself as the nation's oldest continuously operating movie theater. Raymond volunteers regularly at the local live theater organization, the Newtown Arts Company.

Bonal said she got the help she needed from coaches with Integrated Studies, but she still finds it difficult working from her home in Exton, Pennsylvania. "It's very hard, but we are learning new things every day," she wrote in an email in April, while classes continued. "I thought it was going to be easy, because we're home."

She enjoyed campus very much, and she missed it. The hardest thing about taking classes from home, she said, is "you can't talk to the professor and communicate with other students in class."

The change might have been most jarring for Daniel Castellanos. The Press Room restaurant, where Castellanos took such pride in creating salads, closed in mid-March. Two months later, it hadn't reopened, and he'd found no other work.

Unbridled ambitions

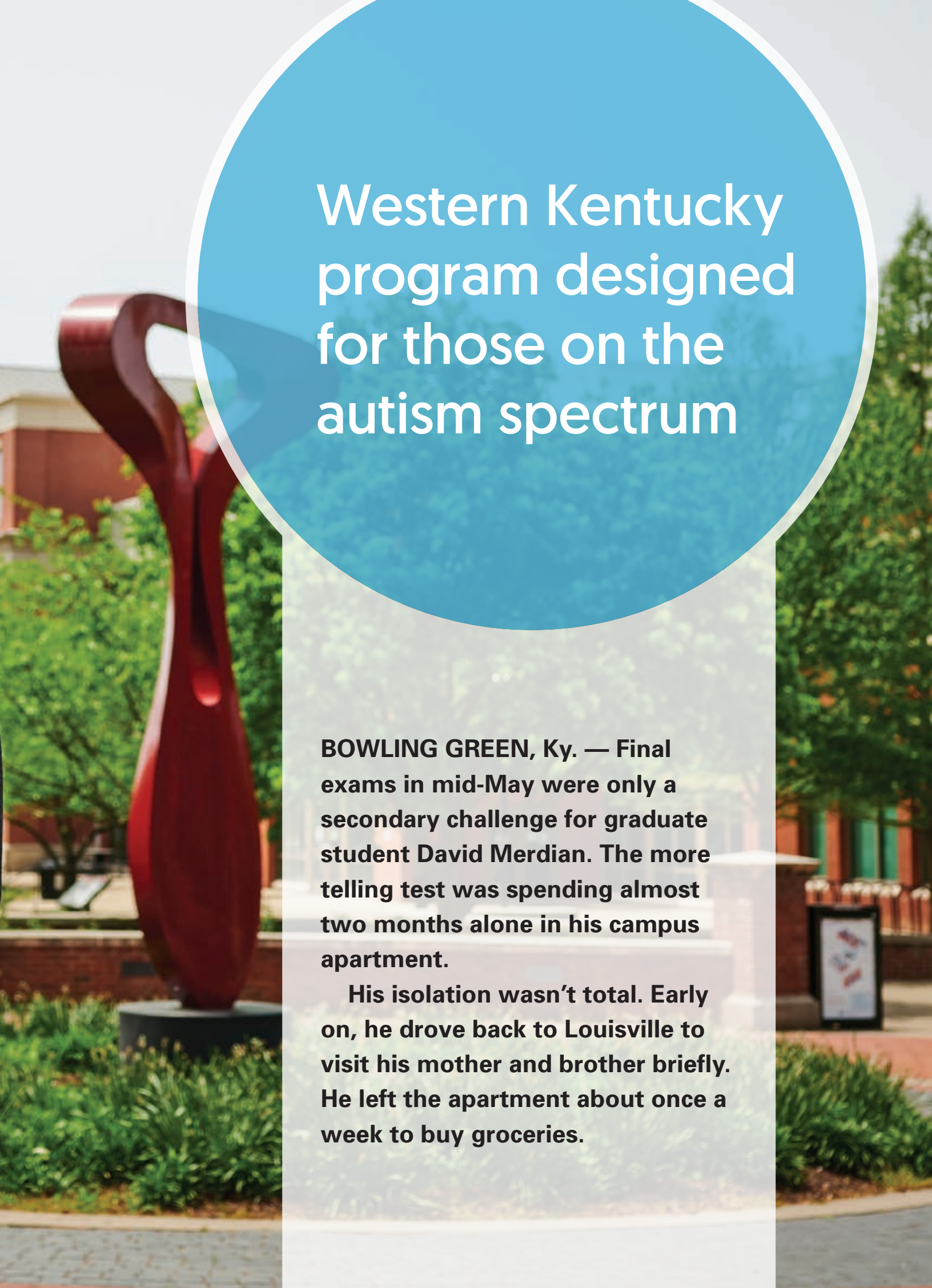
Still, there's no sign that a few weeks off work have tamped down Castellanos' ambition to mix theater, dining, and social justice.

When he was 17, he landed a part in "Curtains," a comedy mystery musical, at J.P. McCaskey High School in Lancaster. He's loved theater ever since. What he's learning about business and restaurants fits smoothly into his plan. "Probably in the future, I'm planning on doing a dinner theater business," he said.

At Millersville, he took a class on public speaking, and that plays into a new aspect he already incorporates into his life's work: advocating for others with intellectual disabilities. In another class, he read Saul Alinsky's book, "Rules for Radicals." Alinsky argues that communities of people who lack conventional political power can organize and gain it. Since then, Castellanos has spoken at professional conferences and testified before Congress.

"For me, being a radical advocate means doing something that you feel is right," he said. "If you look at what Martin Luther King Jr. did, he stood up for what he thought was right for his people. Same thing with Gandhi, who stood up for his people, who wanted the same rights and to have their freedom. I want to stand up and have the same education for students with disability, and to have the right to be independent, and to give the same opportunity as any other regular people." ●

David Merdian, a 22-year-old graduate student at Western Kentucky University, was diagnosed with autism spectrum disorder and ADHD when he was a toddler. He's now in his fifth year in the university's Kelly Autism Program and has earned a bachelor's degree in economics.



Western Kentucky program designed for those on the autism spectrum

BOWLING GREEN, Ky. — Final exams in mid-May were only a secondary challenge for graduate student David Merdian. The more telling test was spending almost two months alone in his campus apartment.

His isolation wasn't total. Early on, he drove back to Louisville to visit his mother and brother briefly. He left the apartment about once a week to buy groceries.

He took an occasional walk. But for a man diagnosed with autism spectrum disorder and ADHD when he was a toddler, so much time with so much less structure could be a pitfall.

Still, Merdian didn't have to navigate the quarantine all on his own. Every week, he spent at least 30 minutes in videoconference with his advisor. With college friends, Zoom became a landscape for Dungeons and Dragons. Early in May, as he studied for three finals, he was confident, and with good cause. Merdian's success in seclusion was built on five years developing skills for success in Western Kentucky University's Kelly Autism Program (KAP). What he learned helped him stay on track. "It's more self-discipline or just willing myself to get the work done," he said.

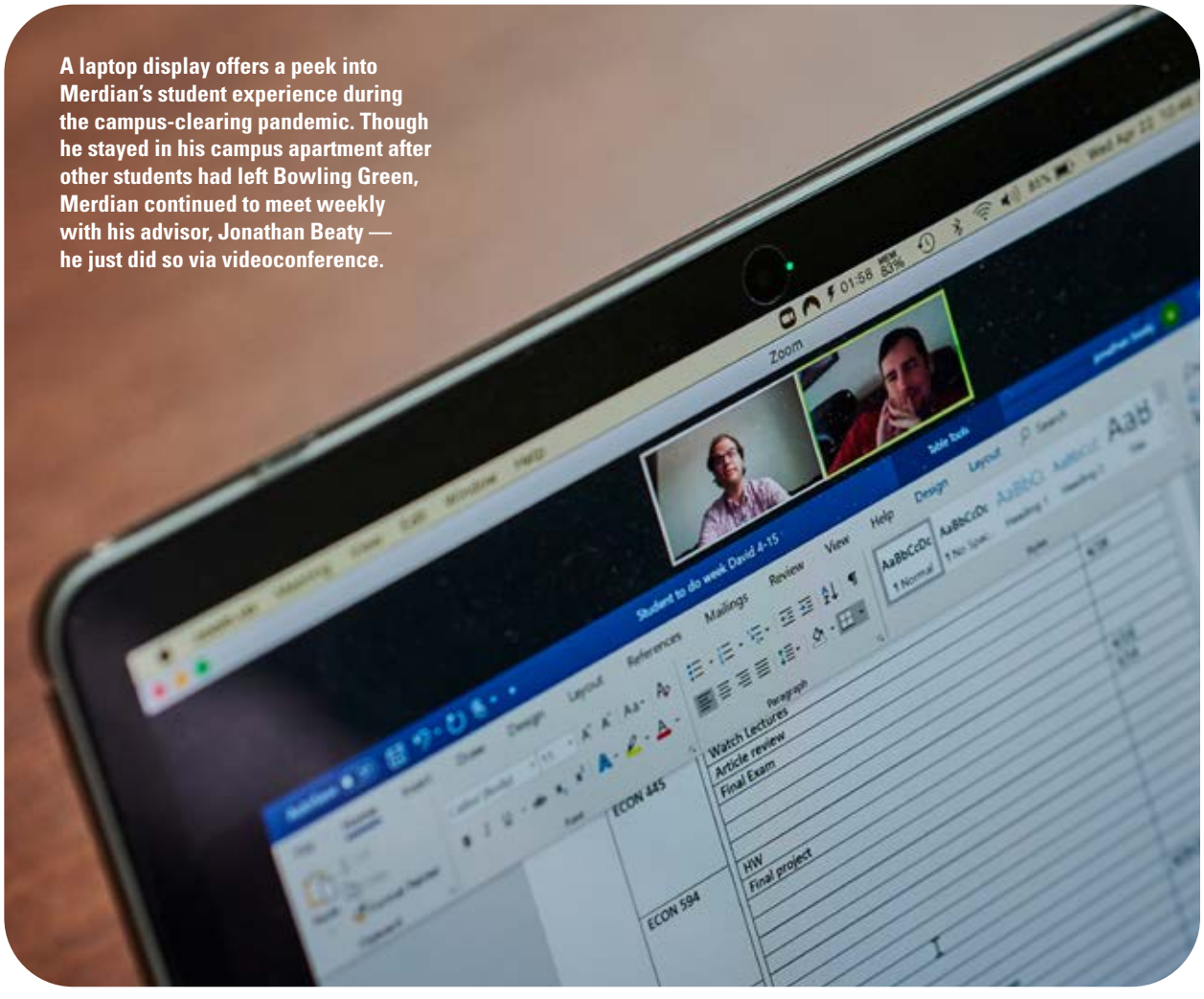
Students who are admitted to Western Kentucky via its normal admission process, but who have been diagnosed on the autism spectrum, are eligible to apply for the KAP Circle of Support. They also must meet other criteria to qualify, including scoring 20 or higher on the ACT, a score that puts a student in the top half of ACT results.

KAP services cover a lot of territory in students' lives, from providing single rooms to requiring 12 hours of attendance each week at "study tables" in the Clinical Education Complex on campus. The complex is the headquarters of the Circle of Support program. Those study sessions are staffed by KAP employees who work not only as academic tutors but also as students' advisors on time management, social skills, and setting priorities. There's a separate mentoring program in which staff work with the 60 students in the program to help them connect socially on campus and with each other. The program also includes a full-time mental health counselor who typically works with about two dozen students at any time.

'We focus on relationships'

When campus closed on March 17 to slow the spread of the coronavirus, the study tables, meetings with advisors, and counseling continued through videoconferences, said Mary Lloyd Moore, executive director of the Clinical Education Complex. She said students' grades have generally been good during isolation.

"We focus on relationships here at the CEC — and building those relationships from Day One. … They had those relationships built prior to the advent of



A laptop display offers a peek into Merdian's student experience during the campus-clearing pandemic. Though he stayed in his campus apartment after other students had left Bowling Green, Merdian continued to meet weekly with his advisor, Jonathan Beaty — he just did so via videoconference.

Merdian has little trouble with academics. His difficulties relate to social interaction. "The nuances of written and spoken language can be somewhat difficult for me occasionally, but body language is one of those things that escapes me almost entirely," he says.

COVID-19," Moore said. "I think that puts them in a much better place than they would have been otherwise."

Merdian, 22, is in many ways a natural for the program. The interlocking services that Western Kentucky provides for KAP students essentially continue nearly 20 years of intensive help led first by his mother, Beth Merdian, and later aided by Trinity High School in Louisville. Now the staff at the university is his chief coach.

Throughout his years in school, Merdian has struggled with "executive function" — choosing from among the many options for spending his time, ranking his priorities, and managing life's daily necessities. Homework assignments, particularly those that aren't interesting, have been a lifelong challenge. His mother recalled this example: "When he was in the first grade … he absolutely refused to do the rinky-dink '2+8' worksheets. He was doing three-digit-by-three-digit multiplication in his head."

Beth Merdian was even then a stickler about homework, and she came to this arrangement with his teacher: If her son submitted to stultifying procedure and did his first-grade worksheets, his teacher would reward him by letting him do fifth- and sixth-grade math worksheets. Since then, she noted, his ability to perform complex arithmetic in his head has dwindled, but she's not concerned. "It doesn't do any good to have those skills that are savant ... if he can't do 10 things that are required for successful daily living," she said.

As a young adult, Merdian's intellectual interests still drill deep. He's never lost the fascination with mechanical watches, trains, and railroads that began when he was a child. More recently, he's delved into more abstract realms, including politics, economics, evolutionary biology, and some aspects of physics. He earned his bachelor's degree in economics, with a minor in legal studies. He's now continuing his economics studies as a graduate student.

"If I'm going with economics as a career, as opposed to becoming a lawyer, then my ideal dream would be to work on some way of reconciling some of the disconnect between micro- and macroeconomics, because microeconomics is a lot like Euclidean geometry," Merdian said. "It's fairly easy to understand for most people once you get the basics down. But macroeconomics basically goes, 'OK, everything you learned — like half the stuff you learned — in micro is either wrong or turned on its head in this context.' It's a lot like trying to reconcile quantum physics and relativity. It's very challenging," he said.

One measure of how well he's responded to coaching on executive function is his ability to keep up with three economics courses this spring. He's still subject to

Advisor Jonathan Beaty says of Merdian: "He's very much a conversationalist. He wants to have a dialogue. He wants to discuss and debate and make friends."

distraction, though. Sometimes, a quick peek at Wikipedia to ferret out a stray reference leads to a two-hour plunge down what he calls "the rabbit hole."

What remains a greater challenge, even after years of work, is navigating social situations. In those settings, Merdian says, having what clinicians used to call Asperger's syndrome "is like being in an unescorted Allied supply convoy in early World War II in the North Atlantic, where there are mines and U-boats everywhere. It's terrifying. … The nuances of written and spoken language can be somewhat difficult for me occasionally, but body language is one of those things that escapes me almost entirely."

Decoding shades of meaning in social encounters is what Merdian and KAP advisor Jonathan Beaty worked on most in their recent weekly meetings. Lately they've focused on learning the conventions of making conversation, and on interpreting the emotions behind others' facial expressions. Beaty offered this example from earlier this year: "I give him little homeworks; like he has a homework this week … He interviewed me about stuff that I like, and now, when we meet together on Friday, he has to have a conversation in which he interjects those things that he learned about me," Beaty said.

"David's big thing is to be able to have a conversation, have a date with somebody, meet people," Beaty said. "He's very much a conversationalist. He wants to have a dialogue. He wants to discuss and debate and make friends."

Circle of Support isn't the only program for college students on the autism spectrum, but only a tiny fraction of U.S. colleges and universities have such programs. College Autism Spectrum, an advocacy organization that studies and promotes college programs for students with autism, lists about 70 programs at U.S. colleges and universities. Jane Thierfield Brown, the organization's director, said that the programs vary in how they emphasize the three key areas in which students on the spectrum often need help: social development, executive function, and employment readiness.

Brown said that families of children with autism sometimes reel when they learn that most colleges charge thousands of dollars a year for comprehensive programs to aid such students. Sometimes families react as if they think "'Gee, (K-12) special education is free. This should be free.' But the college isn't free, and the extra people to work with your kid aren't free," she said.

At Western Kentucky, the cost of the KAP Circle of Support is $10,000 per year. Add that to undergraduate, in-state tuition of $10,802 in the 2019-20 school year, plus room and board charges of around $8,000-$10,500, and the total is still less than the average cost of tuition and fees at private colleges. Another factor makes KAP's work with college students more affordable, Moore said. For most Kentucky residents, the state's Office of Vocational Rehabilitation pays all or most of that $10,000 KAP program fee, she said.

"Some students with autism need a program that focuses more on social, and they need to have more opportunities for safe and comfortable social interaction," Brown said. "Some students really need more from the executive function area in academics and independent living. They may have had a lot of support for that through high school and at home, and that isn't always available in college. Some students need those types of programs, and there are still other students who might need a more employment-readiness type of program, where they have lots of opportunities to practice in real-world work situations."

Employment is elusive

Preparing students for work is crucial. Several studies have found that people with autism, even those who've earned bachelor's degrees, are much less likely to be employed than are neurotypical graduates. In the Western Kentucky program, about 25% of graduates find jobs in their field, Moore said. That's in line with national figures on employment often cited by advocates who promote college education for students with autism. Merdian is better equipped with work experience than many. He had internships in London in 2018 and in Hong Kong in 2019, both involving the collection, analysis, and modeling of data.

Before the pandemic hit, his summer plans included another internship in Hong Kong, where his father lives and works. But as finals approached in May, Merdian said he expected to remain in Bowling Green this summer and take another class toward his master's degree.

Wherever he goes next, it was going to college — particularly the college experience provided by Western Kentucky — that made the difference in his independence.

"This was definitely the first time that I'd been on my own for any extended period of time," Merdian said. "And because of that, and because of the help I was getting from KAP, I was forced to really learn how to take more responsibility for my day-to-day life." ●

"This was definitely the first time that I'd been on my own for any extended period of time," Merdian says of the Western Kentucky program. "Because of that, and because of the help I was getting from KAP, I was forced to really learn how to take more responsibility for my day-to-day life."

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