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A dream to call their own

Young adults with disabilities work on transitioning to a life of independence

By RACHEL KIPP The News Journal

At 17, Alyssa Cowin has her whole life ahead of her -- and on a recent day, she was trying to get it all down on paper.

On one end of a poster-size piece of paper was a marker-drawn star that encased her ultimate goal -to live in a home of her own. Cowin's task was to fill the rest of the sheet with all of the things she needs to start living independently, including building a support system, finding a job and learning to cook nutritious meals.

Surrounding Cowin were a dozen other teenagers who, like her, are young adults with disabilities. Each was at work on his or her own sheet of paper. Two students want to enter school to become massage therapists. One wants to become a forklift driver. Another aspires to be an architect and get married.



The News Journal/WILLIAM BRETZGER STEP student Bill Rineer celebrates after receiving his certificate last week from program coordinator Darlene Arena. (Buy photo)



Alyssa Cowin laughs during the ceremony. Twelve students lived in dorms and spent the week enjoying the perks of college life while taking a step toward independence. (Buy photo)

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The "pathway" activity is one of the first steps toward achieving those dreams on their own terms. The teens spent last week living and learning on the University of Delaware campus as part of STEP, the Summer Transition Education Program.

All of the students are on the cusp of adulthood and the program is designed to help them learn skills they'll need to take control of their lives and make decisions that have always been in the hands of their parents and other caregivers.

"Some people in the system, even though they are caring, compassionate professionals, enable students to become dependent," said Debbie Bain, coordinator of UD's Total Life Project, of which STEP is a component. "Our attitude is 'Go for it, but what will it take to get you there?' We find that many of them have goals that are very realistic but are not sure how to get there."

During the program, students live in a dorm, eat in a dining hall and spend the week enjoying the perks of college life -- exploring Main Street, swimming in the campus pool and making new friends.

"For some students, they've never left home, and this is their first experience," said Darlene Arena, one of the "coaches" who acted as sounding boards and advisers. "Other students have always had a room of their own at home and now they have a roommate and have to share, to compromise, to get up early, to be prepared and to participate."

Some of them are visually impaired, others have autism or cognitive disabilities. Students take classes in nutrition, budgeting, problem-solving and understanding their rights under the Americans with Disabilities Act. Each session is designed so students can apply lessons directly to their particular challenges.



The News Journal/WILLIAM BRETZGER Shanelle Sullivan (left) hugs fellow participant Julia Loftus during their Summer Transition Education Program graduation ceremony. Sullivan wants to become a veterinarian and was able to tour UD's College of Agriculture and Natural Resources during the week. (Buy photo) (Buy photo)

"We believe that people with disabilities can learn these skills and become independent," Bain said. "There are a range of disabilities and a range of possibilities; for these students it really runs the gamut. You'll see some young people graduate high school and go on to a job. Several definitely have the goal of going to college." Meals and afternoon snacks provide more than just nourishment. When students made pizzas at a local restaurant, they also talked to restaurant staff about what it takes to become a chef or to run a business. They learned about tipping and what is appropriate small talk in a mealtime setting.

"So many times people take for granted that everyone knows how to network," Bain said. "But some people with disabilities don't have that innate ability."

Students learn to avoid "closed" questions -- often conversation killers because they require only a "yes" or "no" answer.

"One of the things we talk about is how to engage in open-ended questions and how to interject and disclose information about you," Bain said. "For some of them, asking questions is hard. For some of them, eye contact is hard."

In another activity, Bain brought out several trays of fruit for a snack -- but first, she asked the students to talk about the similarities and differences between the apples, strawberries, grapes, bananas, oranges and limes.

Later, Bain asked student Bill Rineer, 17, to come up to the front and switch shoes with her. After earning a few giggles by clomping around in Rineer's size 12s, Bain held up her own size 5 Keds.

"The takeaway for you is that one size does not fit all," Bain said.



Students identify goals

The News Journal/WILLIAM BRETZGER The program on the University of Delaware campus helps students with disabilities who are on the cusp of adulthood learn to take control of their lives.

STEP is an offshoot of the Total Life Project, an initiative of UD's Center for Disabilities Studies. Some Total Life participants live in a house near campus during the program; the Total Life house also served as home base for STEP.

"Our approach is person-centered," Bain said. "Our primary focus is on the individual: what is important to them, what are their goals and agenda because that is what is important for them to meld into society and into a responsible adult."

While the three-year Total Life program targets ages 14 to 30, the one-week STEP program is focused on young men and women in their late teens and early 20s.

STEP student Michele Ogden, 22, is also part of the Total Life Project. She said the program taught her "how to manage your own money."

"My parents are understanding that I'm going to have to do it for myself now," said Ogden, who is in the process of looking for her own apartment. "I get my own check from work, [but] I may ask for my parents' support."

Six students participated in STEP's inaugural session last summer; 12 students are participating this year. STEP doesn't have a dedicated funding source, but some students got scholarships from other agencies to help pay the \$1,500 tuition.

Each student and his or her parents met with Arena and Bain before the program to discuss the teen's goals for the week. The interviews also helped Arena and Bain identify students who may not be ready for independence.

"Many of the students have had their parents orchestrate their lives," Arena said. "Many times, the parents say 'I'm not going to be here forever -- who's going to care for them?' Some of them have never made a get-together to go to the movies and go for pizza or their caregivers have always done that."

Four of the STEP students spent part of the week in externships related to their goals. Shanelle Sullivan, who wants to become a veterinarian, toured UD's College of Agriculture and Natural Resources.

The 16-year-old high school junior from Newport came back with stories about close encounters with a horse and herds of dairy and beef cattle. She also learned about how much schooling it will take to achieve her goal -- about eight years -- and got recommendations about undergraduate majors that would help her when she applies to veterinary school.

"I'm filling out the application for UD tonight," Sullivan told coach Tanya Servis, who replied with a high-five.

"It's amazing watching them grow and achieve, especially with me being disabled," said Servis, a 2008 UD graduate who is legally blind. "Because I've been given so many, many opportunities and some of these kids haven't."

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