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Creating a map for independent living; UBC's online program for people with intellectual disabilities encourages participants to express their dreams but also manage their expectations

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VANCOUVER -- Callan Parker has what some people call a "diversability." Born with Down syndrome, Ms. Parker has grown into an 18-year-old fashionista with a passion for dancing, Facebook and pop singers such as Hilary Duff.

But like many people her age, she's at a crossroads. High school is over and the path to a job and independent living is uncertain. The road map is getting clearer, though.

Ms. Parker is enrolled in an eight-month course at the University of British Columbia designed to help people with intellectual disabilities find their own way. Launched in September, the Canadian Inclusive Lives Learning Initiative (CILLI) is a pilot program in which participants learn about decision-making, employment, financial literacy, legal matters and how to access outside resources.

Throughout the course, which wraps up in June, Ms. Parker will devote about 10 hours a month to online-learning modules and telephone sessions with facilitators, joined by her father, Michael Parker.

"By the end of it, essentially, Callan will have a life plan," he says.

The program is the most comprehensive of its kind and unique in its approach: People with intellectual disabilities can enroll in the course on their own or with a family member or friend.

"As far as we know, it's the only program like this in the world," says Tim Stainton, co-founder of CILLI and director of UBC's School of Social Work.

The inaugural course has 22 participants from throughout B.C., ranging in age from 18 to 65. In a few cases, parents have joined on their own to learn more about how to support an adult child with intellectual disabilities live a fulfilling life.

The program is funded with a development grant of \$50,000 from Community Living British Columbia and \$12,000 from Human Resources and Skills Development Canada. In addition, Dr. Stainton and his team approached community-living agencies to secure \$1,300 in sponsorship for each participant.

The course begins and ends with camp-style retreats that encourage participants to get to know each other and express themselves in events such as a Canadian Idol-style talent show.

Throughout the activities, program facilitators "really encourage people to have big dreams," Dr. Stainton says, unlike in the past, when people with intellectual disabilities were told not to build castles in the sky.

Ms. Parker says her favourite exercise so far was to create a vision of her ideal life in a collage plastered with images of stylish clothes, gourmet foods and dancing. "I was born to dance," Ms. Parker says, adding that she'd like to be a mom some day.

Her father can see her working with a clothing designer or in some other creative field. "Callan has a lot of talents," Mr. Parker says.

But expectations management is part of the course, too. As participants learn the steps involved in reaching a goal, they come to realize that "dreams are dreams and they don't mean they're going to come true," Dr. Stainton says.

Each month, participants log onto a website to complete a learning module on a topic such as powers of attorney or how to build a network of community support. In addition, participants receive telephone calls from an expert on that month's topic and a program co-ordinator who helps them incorporate what they've learned into their life plan.

So far, no one has dropped out and every participant has handed assignments in on time, Dr. Stainton says, adding, "it's certainly better than I usually get from my UBC students."

Michael McLellan, 32, and Meghan Williams, 30, enrolled in the course as a couple who have lived apart since their romantic relationship began more than a year ago.

"Part of our life plan is living together at some point," says Ms. Williams, who has ADHD and was brain damaged at birth. The couple will need support from social workers, in part because Mr. McLellan has a severe visual impairment, she says, "but we want to be as independent as possible."

Among their goals is to find paid work. Mr. McLellan's dream job is a permanent part-time position with Community Living British Columbia. Ms. Williams is interested in office work such as filing and data entry, she says: "I can do PowerPoint presentations like you wouldn't believe."

In the meantime, Mr. McLellan says, the couple want

social workers and support agencies to acknowledge their goals. "We're hoping that people listen to her plan and my plan," he says.

Garry Pruden, chief executive officer of Community Living Toronto, says CILLI's emphasis on self-directed planning is well suited for highly motivated individuals. But he adds that since only a small part of the learning is done in groups, participants may not build the social connections that lead to mutual support. "Face-to-face network building [is based on] personal experience, not a conceptual experience online," he says.

Nevertheless, participants are active on the program's online discussion board, notes Dr. Stainton. And the Web-based curriculum, spread over eight months, allows individuals and families to cover a lot of ground without getting overwhelmed.

"We know that for a lot of families, it's a busy life with a person with a disability," he says.

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