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Inspirational book, video highlight disabled adults who achieve

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Jeremy McCarthy sweeps up at the end of his work shift at McClatchy High School's teen center for disabled students. McCarthy, 26, who has Down syndrome, teaches golf and takes college music classes.

Photo: lsterling@sacbee.com

Jeremy McCarthy, a softspoken, bespectacled young man in black Nike shoes and a River Cats baseball cap, is juggling a very busy schedule.

"I work here every day," he says, gesturing around McClatchy High School's teen center for youths with disabilities. He also teaches golf, takes college music classes and plays basketball and floor hockey. He travels, dances and, in his rare free moments, enjoys watching wrestling videos.

His latest project? Role model.

McCarthy and other adults with Down syndrome are featured in a new book and video designed to inspire parents who have, or are expecting, children with the condition.

The nonprofit Down Syndrome Information Alliance will be releasing "Dreams in Reality" at its annual Celebration of Hope fundraiser Monday in downtown Sacramento.

About 350,000 people with Down syndrome, a chromosomal disorder that is one of the most common causes of mental retardation, live in the United States. But despite medical and other advances that have greatly improved survival rates and quality of life, the syndrome and the people who have it are seriously misunderstood, said Elaine Linn, founder of the nonprofit group.

The vice presidential candidacy of Alaska Gov. Sarah Palin helped raise awareness of the syndrome. Palin's 6-month-old son Trig Paxson Van Palin, who was born with the condition, became a fixture in her campaign speeches and appeared with the rest of the Palin clan at the Republican National Convention in September.

"Even in this day and age, the diagnosis is often presented as a tragedy," said Linn, who has a young son with the syndrome. "Parents are told that their child will never amount to anything. We are trying to show families of children with Down syndrome that there are some really cool role models out there."

Prospective parents so fear having a child with Down syndrome that about 90 percent of those who receive a prenatal diagnosis elect to abort their fetus, studies show.

"That hasn't changed since the 1980s, as far as I know," said Dr. Joseph Pinter, associate professor of pediatrics and director of the Down Syndrome Clinic at Oregon Health and Science University. Yet, during that time, life expectancy for people with the condition has shot up; many stay healthy and reach their 60s or 70s, Pinter said.

"Not all of these people are going to accomplish a lot, but we need to give them the opportunities to accomplish everything they can," said Pinter. "I don't think you can give people too much hope. I have learned to stop telling people anything about limits."

The Sacramento nonprofit group's goal is to contact "every new and expectant parent" of a baby with Down syndrome, offering them the latest research information, emotional support and referrals, Linn said. The "Dreams in Reality" book and video will be included in a package distributed to each parent.

Sherron McCarthy knew little about Down syndrome until Jeremy's birth 26 years ago. The diagnosis frightened her and her husband, Patrick.

The doctor who delivered the news was grim. The couple had trouble finding a physician with expertise in Down syndrome. Nurses gave the couple pamphlets about the condition, including information about institutions where such children lived. "That was not an option for us," McCarthy said.

Jeremy was a healthy child, without heart problems and some of the other medical issues associated with the condition. The McCarthys worked hard to provide him with the best therapy and education possible. "We were going to make him into the best Down syndrome child ever, and we think we have," said Sherron McCarthy.

He attended mainstream schools, earned a certificate of completion at McClatchy and has attended classes at California State University, Sacramento, and City College.

Today, Jeremy is mostly self-sufficient, although he lives with his parents in Land Park. He makes about \$11 an hour as a recreational aide at the McClatchy High teen center, where young people with disabilities engage in sports, crafts and other activities.

Jeremy McCarthy was the first developmentally disabled person hired at the teen center, and for the past eight years has been a valued member of the staff, said program coordinator Jeff Parmelee. "He's great. He's eager. He's responsible," said Parmelee. "He's willing to do whatever is needed, and he never complains."

In fact, Jeremy loves his job so much that he once passed up a vacation to Hawaii with his family in favor of working.

"They were going to sit around a pool all day, and that's not a good thing for me," he said with a smile. "I would rather be here."

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