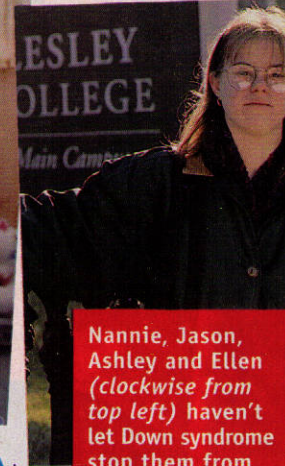


Special Triumphs

Imagine how proud you'd be if, before the age of 23, your child had run for public office, or had a book published to good reviews, or been in demand as a keynote speaker, or received national awards, or appeared on network TV. Now imagine that your child also had Down syndrome.

Increasingly, young people with Down syndrome are achieving great things, by holding down full-time jobs or making the honor roll at school. Yet not so long ago, doctors routinely advised new parents to institutionalize a baby born with Down syndrome: "Go home and forget about her. She will never sit or stand, walk or talk, have a meaningful thought or be a productive citizen. Tell relatives and friends your baby died at birth." Sadly, even today some ill-informed physicians give parents the same advice. But as the following four stories show—and as Nannie Sanchez articulates—"Down syndrome doesn't mean 'I can't.' It just means it takes me a little longer."



Nannie, Jason, Ashley and Ellen (clockwise from top left) haven't let Down syndrome stop them from making their dreams come true.

Down Syndrome Doesn't Mean "I Can't"

Four Success Stories

By Jan Goodwin

NANNIE SANCHEZ, age 24, Albuquerque, New Mexico

When Nannie was in high school, taunts of "retard" from other students, and even from teachers, were common. One classmate made her life hell, frequently sending Nannie home in tears. Last year she spotted him in a fast-food restaurant wiping tables for a living. The irony wasn't lost on her adoptive mother, RoseMarie Sanchez. "Look where you are today, and where he is," she advised.

Where Nannie was, was campaigning for the New Mexico Board of Education—the first time in the United States that a person with Down syndrome had ever run for public office. Like any other candidate, Nannie was intent on winning the hearts and minds of the people—and by all accounts, she was doing a great job. She walked the streets of Albuquerque canvassing, raising campaign funds and giving compelling speeches. Though ultimately she lost to a bilingual special ed teacher almost twice her age, with 18 years of

experience, Nannie won a respectable 38 percent of the vote.

"I lost on that occasion, but I won in many ways," says Nannie. "I've opened the door for people with disabilities who'd like to run for office. I've had experience in organizing a campaign and getting my message—safer schools, better facilities and school-to-work programs—across. I ran because I had concerns about our school system and how people with disabilities are treated. I'll run again next time and, eventually, I'll try for the state legislature. I want people like me to have full inclusion in the community."

Nannie says she learned early that when you're born with Down syndrome, people try to put you in a box. "Forcing you into special ed is easier for the schools, but it's not the best thing for you," says Nannie. Her mom had to sue to get her mainstreamed, and then sue again to get her into college even though Nannie had passed the entrance exam. "When you graduate, you're told there are only three suitable kinds of work for people with Down syndrome: fast food, cleaning up after others, or planting flowers. I think we deserve more choices," says Nannie. ▶▶▶▶▶

Award-winning journalist and author Jan Goodwin is a frequent contributor to FAMILY CIRCLE.

Photos (clockwise from top left): Darren Poore; Dwight Carter; Angela Coppola; Sai DiMarco/Black Star.

swimming, basketball, horseback riding and hiking. She's a gold medallist Special Olympics swimmer and has performed dances that she choreographed. She dates occasionally.

"I never knew if Ashley would have that," said Nancy, "and it's been lovely that she has had the attention of young men. One day last summer, in fact, both of us were sitting on my bed having a time-honored discussion about the opposite sex. It ended with the pair of us shaking our heads and saying, 'Men!'"

Ashley says she'd like to marry someday, "but for now, I'm single and happy." Recently, life threw her another medical challenge. She was diagnosed with fibromyalgia, a complex and painful musculoskeletal disorder. "It doesn't seem fair," says her mother, "that Ashley will have to learn to manage this new health problem." But no one doubts that she will.

"I plan to break social and media stereotypes about people with Down syndrome," says Ashley. "And I can do it just by being myself." She proved that last December when she was cast as a guest star in an episode of NBC-TV's *Third Watch*. Ashley knows that by "having a positive attitude and high expectations for myself," she'll just keep on excelling.

**JASON KINGSLEY, age 25,
Hartsdale, New York**

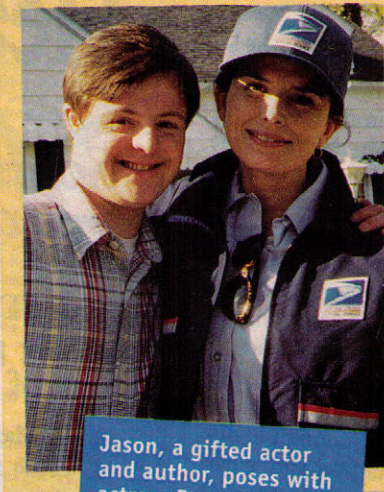
"I'm glad to have Down syndrome...it's not that bad," wrote Jason Kingsley six years ago in his well-reviewed book *Count Us In—Growing Up With Down Syndrome* (Harcourt, Brace), which he coauthored with another teenager with Down syndrome, Mitchell Levitz.

His mother, Emily Perl Kingsley, a scriptwriter for *Sesame Street*, shares his sentiment. "Raising a child with Down syndrome is like landing in Holland when you'd planned to visit Italy. It isn't horrible, just different. There may not be Michelangelos, but you look around and begin to notice windmills, tulips—and Rembrandts."

When Emily was 34 and pregnant with Jason, she was offered amniocentesis, a prenatal test that can diagnose a number of genetic conditions, including Down syndrome. She decided to pass because the test itself carried some risk. "And I am so glad I did. Having Jason has been the most enriching experience of my life. If I'd terminated that pregnancy, what my family would have missed out on is incalculable. And Jason has enriched the lives of millions of people just by his example."

In addition to writing a book, going on a national book tour and appearing on network television, her son has also acted on *All My Children* and *The Fall Guy* with Lee Majors, both of which involved memorizing many pages of script. And every step of the way Jason has been teaching others that "people with Down syndrome have the same hopes, dreams, goals and feelings as other people."

In his book he even has a message for the obstetrician



Jason, a gifted actor and author, poses with actress Roma Downey of the television series *Touched by an Angel*.

who had told his parents to institutionalize him, because he would never learn or even be bright enough to understand his condition. "I would tell him how smart I think that was wrong," wrote Downey. "I would tell him how smart I am. Like learning new languages, going to foreign nations, becoming independent, being a light board operator, an actor. I would tell him that I play the violin and the piano, that I can sing, that I'm in the drama group and compete in sports, that I make paintings, and relationships, and that I have many friends and a full life."

Jason lives independently in his own apartment, pays his own bills, does his own banking, cooking and cleaning. He dates, works out at

gym with a personal trainer, bowls and enjoys *karaoke*. Professionally, he has been assistant cultural arts program coordinator for the Westchester Association for Retarded Citizens, traveling with art shows, cataloging art, doing computer work. Now he has a computer job in the Westchester County Clerk's office.

"Jason excels in some things and less in others," says his mother. "He will never be able to drive a car, for example, because his reaction time and coordination are not good enough, but that doesn't mean he won't write poetry." If there is one message both Jason and Emily want to get across, it is this: "Don't write a child off ahead of time or make assumptions about how far he will go."

"So much of the medical literature that asserts these kids can't learn is based on children in institutions," says Emily. "But place anyone in an institution with no stimulation, no affection, no exercise, no education, and terrible

Don't write a child off ahead of time or make assumptions about how far he or she will be able to go.

food, and even Einstein would come out as uneducable. Not all kids with Down syndrome will accomplish on Jason's level, but they can still make a contribution, as long as parents keep expectations high, encourage them to reach for more and refuse to let anyone keep them from trying."

**ELLEN KUHN, age 20,
Bethany, Pennsylvania**

With her red cap and gown, beaming smile, and aura of self-confidence, Ellen Kuhn strode across the stage last summer to receive her high school diploma. She was making history as the first child with Down syndrome in her county in rural northeastern Pennsylvania to graduate from high school after being mainstreamed. And it is Ellen's self-confidence that has marked her every accomplishment. When she didn't have a date for

the junior prom, she chose not to do what generations of dateless girls have done: stay home out of embarrassment. "I like to dance," she says, so she bought her own ticket and went alone. At the senior prom, a date was no problem, and Ellen and her partner danced the night away. "She was dazzling," says her mother, Johnna.

Ellen's self-assurance has its roots in advice given to her parents when she was born. "Pick her up, take her home, and treat her like any other child," their progressive physician told them. "That's exactly what we did," says Ellen's father, Paul. "And since she was our first child, she was 'normal' to us."

Like many children with Down syndrome, Ellen was born with a hole between the chambers of her heart, which required corrective surgery when she was two. "Until then, she only weighed 12 pounds and had little energy," says Johnna. "She stood up for the first time in her hospital crib after surgery. After that, she started galloping around. We gloated over all of her achievements—feeding herself, talking, walking. It was as if a door had been opened, and Ellen had stepped through it.

Later, however, Ellen's parents ran into the same problem many Down syndrome families face of having to fight school authorities who wanted to confine Ellen to special ed. "When I tried to enroll her in first grade, they said, 'There are special schools for that kind of child,'" says Johnna. "So I told them to just give it a try. It went very well, better than anyone expected. Ellen adjusted and found her way. But then, she always does. She's so outgoing. It's impossible not to like her. Years later, the elementary school principal told me that he'd thought we were crazy to mainstream her. He'd kept quiet at the time, and now he says it was the best thing we could have done."

Ellen has always been high functioning. She fits in well wherever she goes and she has an astounding memory. "She'll watch a video or musical, and tell you every word and motion afterward," says her mother. "That may be why she's a great performer—and has never had stage fright."

The Kuhns found that as they battled to have Ellen accepted, school authorities frequently treated them as though they, too, were retarded. "They'd talk down to us, and sometimes people even behaved as though Down syndrome were contagious. People are clearly fearful of something they don't understand. But then, you know, I've just been through breast cancer, and a lot of people behaved the same way. One way or another, however, we Kuhns are survivors."

In Honesdale High School Ellen bloomed. At the Kuhns first meeting with the principal and vice principal, they were treated like dignitaries. "Oh, the difference," recalls Johnna, smiling. "They seemed to recognize that if Ellen did well there, it was a



Ellen (center) celebrates her accomplishment with fellow graduates on the day of her high school commencement.

Ellen could turn your mood around. She has a talent for bringing out the best in people.

feather in their cap, too. One teacher told us: 'Whatever you need, we're going to make it happen.' Consequently, Ellen loved her teachers."

"We were always being told that when people were having a horrible day, Ellen would come bopping into a class and, with her wonderful social skills, just turn everyone's mood around. She has a talent for bringing out the best in people. Ellen doesn't think twice, for example, before giving a hug to the principal, or even to the tough teacher everyone else is terrified of."

Johnna says she tries not to wonder why Ellen was born with a disability, "but sometimes I think that her reason for being here is her sunny disposition, her ability to make others feel good about themselves. I think the world is a better place, both for the disabled and the rest of us, because of her presence. I've learned a lot from Ellen. And she still surprises us with how much she can accomplish when given the chance."

Says Kathy Highhouse, one of Ellen's former teachers, "She's a wonderful kid. Everyone loves her. She paved the way for a lot of children."

Ellen isn't yet sure of her future plans. Currently, she's apprenticing in a local restaurant, "to get a feel for the workplace," she says. "I've also been promised a job at a supermarket. I'm still not sure what I want to do." ■

Where to Turn for Information

Down syndrome is the most commonly occurring genetic "accident" in humans. It's estimated that the condition affects some 300,000 Americans, and occurs in one in 800-1,000 live births. For more information or educational referral services, contact: • National Down Syndrome Society, 666 Broadway, New York, NY 10012. Phone: 800-221-4602; Fax: 212-979-2873; Web site: www.ndss.org or • The National Down Syndrome Congress, 7000 Peachtree-Dunwoody Road, N.E., Building 5, Suite 100, Atlanta, Georgia 30328. Phone: 800-232-NDSC or 770-604-9500; e-mail: NDSCCENTER@aol.com