FOR NAIA AND HER FAMILY, DAILY EXISTENCE - WITH ITS PROGRESS AND PITFALLS - IS AN EXTRAORDINARY TRIUMPH


ABSTRACT (ABSTRACT)

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When Naia was 2 1/2 and Cole was nearly 6 months old, [Ernie Temple] had yet to touch Naia or even set eyes on Cole. It was time, Tierney decided, to write him a letter. In it, Tierney recounted his arguments against mixed-race unions and explained why his sentiments had hurt so much. She asked if he realized how much she had needed him during Naia's difficult first year and how hard it was not to have had his support. "I do love you, Dad," she wrote.

1. Naia Fairchild on the lap of mother Tierney, with father [Greg Fairchild] and brother Cole. Naia's Down syndrome brings its own set of challenges, but her advances are special cause for joy. / GLOBE STAFF PHOTOS / SUZANNE KREITER 2. Naia, who will be 4 in November, visiting her grandmother in Connecticut, where the Fairchilds once lived. They have relocated to Virginia; there, Naia attends day care and has made many friends. 3. Naia fits right in with the group at day care. "She is like any other child in this class," says teacher [Donna Robinson]. / GLOBE STAFF PHOTOS / SUZANNE KREITER 4. REVISITING NAIA [Naia Fairchild] shows developmental delays associated with Down syndrome - and also defies stereotypes about the condition. Her parents, whose decision to continue the pregnancy was the subject of a Globe series in 1999, maintain a goal for her of a productive and independent life. / (PHOTO ON PAGE A1) / GLOBE STAFF PHOTO / SUZANNE KREITER

FULL TEXT

CHARLOTTESVILLE, Va. - "Grapes, Mommy... Please." It sounded like "Gapes, Mummy... Peas." But Tierney understood. In December 1999, the Globe published a six-part series called "Choosing Naia: A Family's Journey," about a couple's decision to continue a pregnancy after learning their child would have Down syndrome and a heart defect. Globe special projects writer Mitchell Zuckoff has expanded and updated the story in a new book, also called "Choosing Naia." This story is adapted from the book.

"You're still hungry? You want grapes, Naia?" "Yes, Mummy. Gapes."

"It's late, Naia. I'll give you three grapes."

"No! Five gapes. Five gapes!"
It was a kitchen showdown. Tierney looked at Naia. Naia stared back. Not far off, a baby gurgled. A mantle clock ticked loudly.

Someone had to blink or all hell might break loose.

"OK, Naia," Tierney said, her voice thick with exasperation leavened by pride. "Five grapes."

As strong-willed as her parents, as challenging as any toddler - with a healthy appetite, a healthy heart, and a healthy sense of childhood entitlement - Naia Fairchild knew she had won again. Gracious in victory, she sweetened her voice: "Thank you."

"You're welcome," Tierney said, handing over the loot.

Naia gobbled the grapes, then threw her hands triumphantly into the air: "All done!"

Nearly two years had passed since Naia’s first birthday party at her grandmother’s house in Avon, Conn. As she approached her third birthday, Naia was straddling the line between babyhood and big-girldom. Her achievements were more apparent than ever, though some of her challenges were more evident as well.

Testing by professionals and back yard comparisons to other children revealed that Naia had many of the anticipated developmental delays of Down syndrome. But those same formal and informal measures demonstrated that Naia defied stereotypes about the condition. And her parents, Tierney and Greg Fairchild, were more certain than ever that it was too early to accept limits on what she might accomplish.

Like all parents, they had goals for their daughter, and they hoped to make them Naia’s goals, too. Short term, the goals were clearer speech and strengthened muscles, better fine-motor skills and improved coordination. Long term, there was one overriding goal, the same goal all caring parents share: a productive, independent, and happy life.

In the years between her first birthday and her third, Naia had climbed the first rungs of that ladder. She had moved from crawling to dancing, from tentative steps to bursts of running, from a few simple words to a vocabulary of several hundred. Her words were sometimes hard to make out - Naia sounded like "Yaya" - and her sentences were mostly two- and three-word combinations. But she could make herself understood.

She could count to 12, higher with help. She had gone from sucking a bottle to feeding herself with a spoon, from soiling her diapers to seeking out the toilet. She knew her colors, the names of different shapes, and major parts of her body. She sang songs - "Wheels on the Bus" and "Ring Around the Rosie" were favorites. Sometimes she skipped words or mixed things up, but she knew the hand and body motions that went with the tunes.

Although she wasn’t as verbal as most of her typically developing peers, Naia followed along patiently and intently - better than many other 3-year-olds - when her parents and day-care teachers read picture books aloud. She knew the letters of the alphabet, and she liked to crow about it.

"What’s after E?" Tierney asked one day. "F!" Naia yelled. And when she spotted a sign in a store, she called out: "Mommy, look - M!"

To improve Naia’s communication skills, speech therapists taught her sign language, reinforced at home by
Tierney and Greg. She often used the sign for "all done" - sweeping her hands aside, like birds in flight - and she added more signs on a regular basis, including "please," "eat," "more," "read books," and "play."

She could be stubborn, and sometimes she demanded Tierney's attention with increasingly loud and intense calls - "Mommy? . . . Mommy?! . . . Mommy!! Momm-ee!!!! Momm-eeeeee!!!!!!" - until Tierney dropped whatever she was doing and focused on her. Naia was just as passionate when expressing her feelings. She hugged with abandon. She kissed with conviction. When Greg's father visited, he was a favorite target - "Kiss Paw-Paw!" she would yell before surrendering to sleep.

Like most people with Down syndrome, Naia was small for her age. At her third birthday, she was 2 feet 10 1/2 inches tall and weighed 27 1/2 pounds. That translated as the 75th percentile for height and about the 60th percentile for weight among girls her age with Down syndrome. She was on the very low end of the growth chart for typically developing children, just as she had been at her first birthday.

Naia had shed much of her baby pudge, and her facial features were defining themselves more clearly and adorably. Her hair was as silky and fine as it had been in infancy, but it had grown into the long, loose curls of a very young lady. Her looks drew people to her.

The characteristic features of Down syndrome were evident - around her eyes and the bridge of her nose, in particular - but they remained subtle. Some people didn't realize she had the condition, while others spotted or suspected it right away. Another tip-off that something was different was the faint surgical scar down the center of her chest.

That was the only sign of the health problems that had dogged her early months. Dr. Lee Ellison's heart repairs had held up flawlessly. Naia's only health concerns were her frequent colds, which most likely resulted from her small respiratory passages, a common effect of Down syndrome. Other than that, she was hale and hardy.

"I am just joyful about Naia and her growth and development," Tierney said one afternoon when Naia was nearly 3. "I have to temper myself and say, 'Tierney, just brace yourself; at some point that might change.' But that point hasn't happened, and Naia is just a delight."

Six weeks after Naia's second birthday, the Fairchild family welcomed a new addition. Tierney gave birth to a son: Cole Christian Fairchild.

He was a jovial, adorable, placid fellow who bore a strong resemblance to his big sister. But in addition to his gender, there were two major differences: Cole had a typical complement of 46 chromosomes per cell, and his heart was free from defects.

And yet, despite all they had been through, Tierney and Greg hadn't known whether Cole would be diseased or disabled - and hadn't done anything to find out - until the day he was born. As much as they valued having learned about Naia's condition in advance, as much as they were thankful that prenatal testing had allowed them to make a choice about the pregnancy with Naia, their thinking had shifted dramatically. They didn't want am nio cen te sis or any other test that would count Cole's chromosomes. This time there would be no uncertainty about whether to proceed or abort. They still believed in abortion rights, but after Naia the only choice for them would be to continue a pregnancy.

"If God is going to bless us with another child with special needs, we weren't going to do anything about it,
anything to stop it," Tierney said.

"We already know what to expect from Down syndrome," Greg said with a shrug.

The other big changes in their lives involved where they were living and working. A few months into Tierney's pregnancy with Cole, the family moved from Connecticut to Charlottesville, Va., where Greg joined the faculty of the University of Virginia as an assistant professor at the Darden Graduate School of Business Administration. It was a homecoming: Tierney and Greg had both received degrees from Darden, and they had wed in the UVa chapel.

Tierney, meanwhile, had proved too valuable to United Technologies Corp. for her bosses to let her go. They made her manager of executive education and development, and as a bonus she could do the job largely from an office at the Darden School not far from Greg's.

The Malcolm Cole day-care center, a five-minute drive from Greg and Tierney's house, was located in a modern, two-story brick building that could hold up to 170 children. Naia was the center's first and only child with developmental disabilities.

The room where she spent her days was clean, bright, and filled with tiny chairs. Labels were affixed to all the furniture, as well as to a mirror, a pencil box, and anything else that would hold still. On a wall were pictures students had made by pasting leaves onto paper trees. Naia had glued six leaves onto her tree - fewer than some of her classmates, more than others.

Outside the building was a large play area with climbing structures, slides, and an oval track for tricycle riders. Best of all, as far as Naia was concerned, the yard was next to a rail line where she could press up against the fence and watch CSX freight trains rumble past. Sometimes she would count the cars.

On a warm fall day, Naia and her classmates spent much of their time outside. Her hair pulled back in a ponytail, Naia wore blue pants and a white shirt decorated with generous helpings of her lunch. She was shorter, less agile, and less verbal than most of her friends, but she was clearly a member of the group, subject to all the good and bad.

At one point, Naia was among several children playing in a sandbox, digging holes, making tunnels, and grabbing toys from one another's hands.

"Naia, you have to wait!" yelled a little girl named Hannah, gripping a yellow shovel.

"Wait," said Naia. When she got bored of waiting, she climbed out of the sandbox.

"Naia! Come back!" Hannah called.

But Naia was already off to join a new group of friends playing with hula hoops.

"I gave Naia a hug," boasted a little boy named Bennie.

Naia's teachers, Donna Robinson and Pam Bryant, kept an extra eye on her, but they only occasionally needed to intervene as Naia made her way around the yard.
"I was unsure of myself in the beginning," said Robinson, a 12-year veteran of the center. "I wondered, 'Am I going to be able to help this child?'"

A year later, those worries were gone. "The way I see it now, she is like any other child in this class," she says. "They are all different, and they all need to work on different things. This one might need help with social play, and that one might need work on language. We help them all."

Although life for the Fairchild family was moving smoothly ahead, a painful gap remained. Greg and Tierney still didn't know whether Tierney's father, Ernie Temple, would overcome his objections to their interracial marriage and become part of their lives.

When Naia was 2 1/2 and Cole was nearly 6 months old, Ernie had yet to touch Naia or even set eyes on Cole. It was time, Tierney decided, to write him a letter. In it, Tierney recounted his arguments against mixed-race unions and explained why his sentiments had hurt so much. She asked if he realized how much she had needed him during Naia's difficult first year and how hard it was not to have had his support. "I do love you, Dad," she wrote.

Then Tierney asked her father three questions: Do you think black people are inferior? Can you accept your mixed-race grandchildren? And, if we see one another again, will you treat us with respect and acceptance, or should we expect endless replays of past battles?

Ernie replied a month later. "I do sincerely apologize for having said anything that may have led to or caused any of the unrest between us. . . . Getting to the chase, I do not believe any race to be inferior to any other in any way." He continued: "As my daughter, I always have deep feelings about your ongoing well being. And for you and Greg, I sincerely respect who you are and your excellent stations in life, and wish you both Gods speed. The downside is simple in that I think I enjoy other activities more than your good company. . . . Sincere congratulations to both of you for Naia and Cole! . . . The best of health to everyone and all, with my best regards, Dad."

Sometimes Tierney focused on the harshest portion of the letter, the part about Ernie not enjoying their company. "We are just very different people, and for whatever reasons Dad wants to say, and whatever reasons we want to say, it's honest to admit that we really don't enjoy interacting with each other. That's OK."

Other times the letter soothed her. She allowed the words to salve hurts that dated to her childhood, when she was the low child on Ernie's totem pole. It was those times when Tierney read the letter as a sincere apology, in whose text and subtext she could find an awkward expression of a gift she had longed for: her father's approval.

"I feel like I don't have to be sad anymore," she said. "I feel like he has taken great strides to understand and compliment me for who I am, even if I've caused him pain."

Tierney and Greg continued to enjoy close ties with Tierney's mother, Joan Temple, and sister, Tara Temple, and Greg's parents, Bob and Mary Fairchild.

"No one is without a gift," said Tierney's mother. "When you find it, that's where you belong. Naia will find hers, and she will give back to others. There's no question in my mind that anyone who touches her life will be blessed."

Tara, meanwhile, began building a family of her own. She married an environmental engineer named Gary D'Oria, and together they began thinking about having children. When Tara looked back on Tierney and Greg's decision,
and ahead to one she might someday face, her evolution from doubter to supporter became clear.

"I got a sense early on that Tierney and Greg's lives were going to be richer, that they were going to be rewarded," Tara said. "I realized that what they did can make the difference between an ordinary life and an extraordinary life."

Bob and Mary were the biggest beneficiaries of Tierney and Greg's move to Virginia. Living less than two hours away, they visited often.

"I think Naia is going to be able to integrate and be part of the mainstream throughout her life," Bob said. "She'll always require some additional assistance, but I think she'll be fine. She has a tremendous amount of potential."

"That's where family comes in," said Mary. "That's your surety in life. Your family is always there for you, and so it will be for Naia."

A few weeks before Naia's third birthday, she toddled around the living room holding her favorite doll, a modern-day Raggedy Ann called a Groovy Girl, with caramel felt skin and a funky wardrobe.

On one of her room-to-room circuits, Naia noticed her baby brother sitting in the family room off the kitchen. "Hi, Cole!" she called out with a Scarlett O'Hara accent. He looked at her and burst into a two-tooth smile. When she walked away, he grew sad - he was immobile, a few months away from walking - so she turned back.

"Don't cry, Cole," Naia said, "Don' cra', Coe" - and patted him on the head.

Later, Tierney came home from work and read books to both. Soon it was bedtime, and Greg came upstairs and said good night.

"Night, Daddy," Naia said.

"Good night, big girl," he answered, smiling.

Tierney swept Naia over the rail into her crib. But she wasn't quite ready to sleep.

"Pray," Naia said.

"You want to say your prayers, Naia?" asked Tierney.

"Yes."

Naia stood inside her crib, her palms pressed together in the steeple of prayer.

"OK," Tierney said, "who are we going to pray for?"

"Mommy!" Naia said.

"OK, Naia. God bless . . ."
"Who else?"

"Daddy!"

"Who else?"

"Tissues."

"Tissues, Naia?"

"Yes."

"OK, tissues. Who else?"


"Baby Bop? From Barney? OK, Baby Bop. Who else?"

"Ice cream."

"No, not ice cream. We're praying for all the people."

"Bennie. . . . Donna. . . . Pammie."

"Everybody from school?"

"Yes."

"OK, say it with me, Naia: 'Keep them safe and healthy.'"

"Healthy," Naia said.

"Say 'Amen.'"

"Amen, Mommy."

"Mommy loves you."

"Kisses, Mommy!"

Tierney leaned in for her good-night kiss. She turned out the light and tiptoed from the room. Her day complete, Naia lay down and went gently to sleep.

Mitchell Zuckoff can be reached at zuckoff@globe.com. He is scheduled to discuss "Choosing Naia" next Wednesday at the Boston Public Library and on Oct. 19 at the Fairmont Copley Plaza as part of the Boston Globe Book Festival. The Fairchilds will be the subject of an upcoming hour long "Dateline NBC" special.
Illustration
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