

when the least restrictive environment is residential: meeting the needs of our son

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offers the unique perspective of a parent and professional. A North Carolina resident, Morris is most proud of being a wife and the mother of three amazing children. She welcomes questions and comments about this article at djenmemorris@gmail.com and www.todaywithdjenne.com.

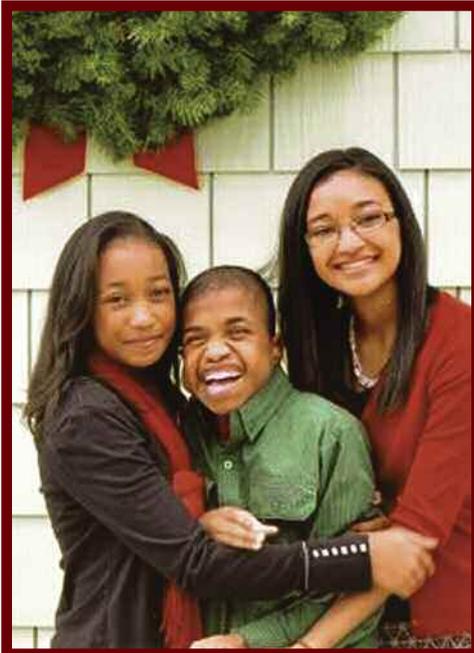
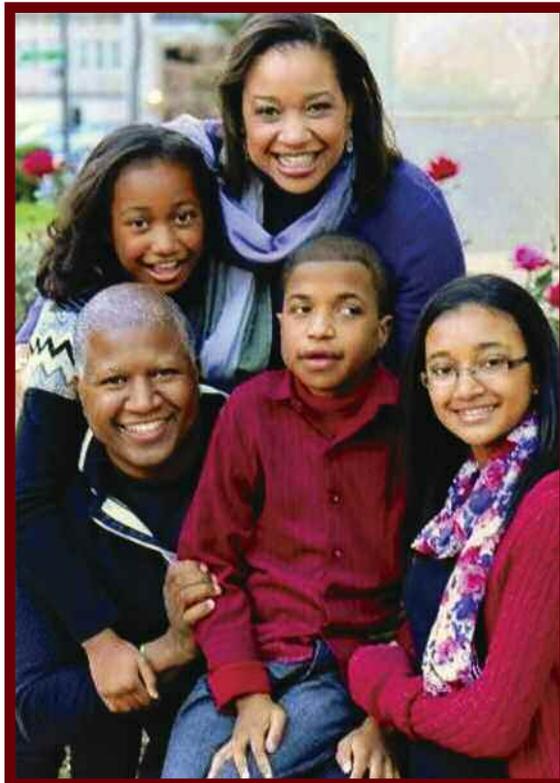
By Djenne-Amal Morris

Malik-Asante Lamar, whose name means “the King that we are thankful for who is destined to do great things,” was born in 1996, just 13 months after his big sister, Imani. The excitement of having our first son soon turned into a medical and emotional nightmare when he was diagnosed with tracheal esophageal fistula, a hole between the four chambers of his heart, and coloboma, a cleft in the iris of the eye that causes vision loss. It did not stop there. Within 48 hours, we’d been told that Malik was profoundly deaf, legally blind, and developmentally delayed. Our beautiful baby boy was also fighting for his life, but he had a strong will and spirit. He wanted to live! My husband, Michael, and I embraced him, and we braced ourselves for the unknown roads that lay ahead.

During his first three years, Malik received intensive therapies from amazing practitioners at state agencies and the Perkins School for the Blind in Watertown, Massachusetts. At age 3, he was diagnosed with CHARGE Syndrome, a genetic anomaly that underlay his medical condition. This knowledge didn’t change our situation. We assumed that he would transition into the pre-school program at Perkins and remain there for his education. We did not anticipate an educational battle with our local school system. However, when Malik turned 3 and was no longer eligible for early intervention services, this is exactly what ensued. Over the next five years, we tried to convince our local school system that his current placement was, indeed, the least restrictive for Malik.

Photos courtesy of Djenne-Amal Morris





At Perkins, they were familiar with CHARGE syndrome, and Malik was having his educational and medical needs attended. Our local educational agency (LEA) contested his placement, however, claiming that Malik could be successfully educated at the public school for deaf children. Unfortunately, this school did not have a teacher experienced in educating deaf-blind children, or the medical staff to handle Malik's tube feedings and nutritional maintenance, or the knowledge to handle what was then a fragile child through the variety of complex situations he would encounter throughout the day. If Malik attended what was the nearest public school, his day would be constantly interrupted as inexperienced personnel attempted to care give, and little learning would take place. Still the LEA was determined that Malik be removed from Perkins. We were equally determined that Malik not be a part of a program that did not yet

exist or that would be created for just him and did not include peer interactions or qualified staff, and we realized that we needed legal representation. This came in the form of a terrific lawyer, who happened to have coached my husband in high school soccer. We worked together to prove—not once but multiple times—that Malik needed to remain where he was. We found many allies, including a newspaper reporter who kept our story in the public eye, and doctors who wrote countless recommendations for Malik's placement at Perkins. After years of three- to four-hour meetings where we argued, the LEA finally seemed to accept our decision, though perhaps she was just worn down.

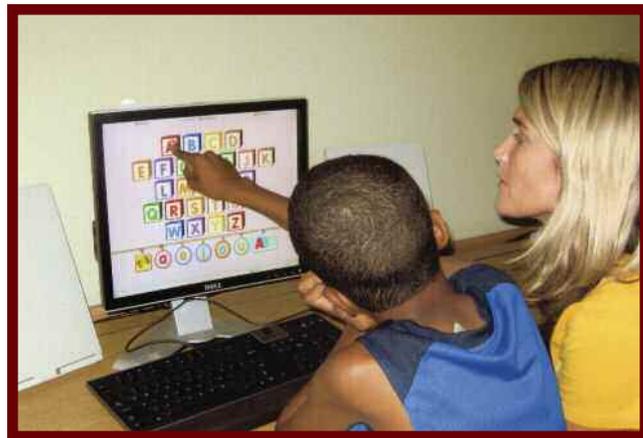
Meanwhile, Malik had become a handsome charmer. He was making friends, gaining weight, learning to sign, and had his amazing teachers wrapped around his finger. He zoomed around with his walker until he

took his first steps independently at age 6. By the time Malik was 8 years old, our family had grown yet again, and Malik now had two sisters. The northern winters seemed to be wreaking havoc on his young body, and we decided it would be best for our family to move south. I found that Eastern North Carolina School for the Deaf (ENCSD) had a program in which Malik would fit nicely. The placement was residential. This, of course, was the hardest decision I'd ever had to make. Still, I realized that it was the best place for Malik to grow and learn. He would benefit from the sign language immersion, peer interaction, and on-site medical facility. It would be best for the rest of us, too; we would be able to focus on the needs of the girls without the constant requirement of meeting Malik's needs around the clock. We would have a bit of normalcy.

Perhaps we should have expected it, but once we moved the educational nightmare blindsided us again. Our new LEA thought that the local school district—which had never enrolled a child like Malik with his specific and intense needs—should be where he was educated. I thought I had awakened from that dream! Here we go again, I told my husband. However, we had practice now. We immediately found an advocate, a person from the Exceptional Children's Advocacy Center. I was put in touch with the center by my parent educator at Beginnings for Parents of Children Who are Deaf or Hard of Hearing, the organization with which I now work as a parent educator. We called the newspaper and rallied to present our case to the LEA. Another round of endless meetings followed. We dug in our heels; we wanted our young King to receive the education he deserved. Fortunately, this process didn't take quite as long as last time, and Malik was placed in ENCSD, where he still is today. At ENCSD, he is taken care of by a great staff. This includes two deaf-blind interveners—individuals who

are deaf-blind. Both of these individuals are deaf adults, and they help Malik navigate his world, gather information, gain independence, and improve his self-help and communication skills. Malik is in heaven. He goes to school Sunday through Friday and hangs out with his family on the weekends, so he has the best of both worlds. He has made friends, his ability to communicate has improved, and his health, while still up and down with viruses and respiratory issues, is as stable as it has ever been. Our biggest challenge today is that we now have a teen on our hands!

A new, scary yet exciting, world opened up on the day Malik was born, and I would not be who I am or know the wonderful families that I know without him. What a journey this has



been! Has it always been smooth? Surely not. It's been a journey paved with fear, uncertainty, hospital stays, and sleepless nights. I've faced recurring crises—over the mortality of my child, the sanity of my family, and the challenge of keeping a marriage together and strong, all while trying to hold on myself. Still, because of Malik I have found my life's work: supporting families of children with special needs and the professionals who serve them. For this work, for my son, for our two daughters, and for my husband, I am grateful.

WHEN FIGHTING THE GOOD FIGHT

Tips for Parents

By Djenne-Amal Morris

- **Don't doubt yourself as a parent.** You are the true expert on your child. Remain confident that you know your child's needs the best. Trust your gut—sometimes instinct is the best guide.
- **Activate your support network.** Identify those—friends, family, coworkers, parent groups—that can give you honest advice, help you advocate for your family, and provide a shoulder to lean on when you need it.
- **Persuade with perfume!** Assume the best and think creatively and collaboratively to find solutions. Show gratitude.
- **Don't wait...escalate!** When you realize that you can't handle it alone, get help from the experts—educational, legal, social, and psychological.