

Autism Awareness Month



The Austin Family, Photo courtesy of SPARK. Autism Awareness Month Feature Presented by SPARK.

How One Family Learned of Daughter's Special Gift of Autism

By MARINA SARRIS

The Austins suspected that their middle child, Camryn, had autism, but her teachers and doctor did not. Perhaps it was because Camryn did not fit the traditional picture of someone with autism. Camryn is talkative, female, and Black. Camryn was one of only a handful of Black children in her small, rural school district, says her mother, Kristin Austin. Austin worried that, if she kept pushing the school to evaluate her daughter for autism, it might affect how teachers viewed other Black girls.

The family moved to a larger, more diverse area, where Cami, as she's called, could get the help she needed. Cami's new school diagnosed her with autism in 2021. The desire to help others like Cami led the Austins to SPARK, the largest research study of autism. "I started scouring the web to inform myself and equip our family with what we needed to support her, as well as ourselves, and SPARK kept coming up as a leading source of research in autism," Austin explains. "While we're very interested in Cami's personal development, we are also interested in understanding the broader landscape of what the autism community represents, the challenges, and opportunities."

Austin is a professor with a doctorate in education. As she learned more about autism, she realized that studies often did not

include girls of color. The family joined SPARK to help change that. They provided DNA samples to SPARK researchers, who are looking for more genes that cause autism. As Cami grew, her parents saw that she struggled with social skills, attention, and behavior. Two preschools that she attended also noticed: they each found her behavior to be too disruptive for them. Austin expressed her concerns about Cami's social problems, but Cami's many strengths derailed those conversations.

Cami is smart with an advanced vocabulary and a great memory. At 4 years old, she could recite the periodic table of elements, which most students do not learn until high school chemistry class, her mother recalls.

She also had traits common to autism. They included being very sensitive to certain fabrics, sounds, and smells; repeating phrases (which is called echolalia); obsessive and compulsive behaviors; and running from the classroom or hiding under a desk when she felt overwhelmed. "People would constantly write off our concerns, saying, 'She's just advanced, she's gifted, she's bored.' They would get distracted by what she could do and minimize the areas that really needed development," Austin said.

The Austins got along well with Cami's elementary school teachers. But, as one of the few Black families in the small district, they considered carefully how hard they should push for her to be evaluated for her developmental differences. "When you are a family in that type of environment, it's possible that you are overly cautious about what decisions you make with your own children because it might skew the

future of other Black children," explains Austin, who has studied and worked in the field of diversity, equity, and inclusion.

She worried that any diagnosis Cami might receive there could create stereotypes or biases, simply because the school district had very limited experience with Black children. "We didn't want the way Cami appeared to be, to lead to the overdiagnosis of other Black children," she explains.

Like her mother, 11-year-old Cami is interested in people understanding more about autism, especially how it affects people differently.

"I really want people to know that if someone tells you they have autism, believe them," Cami says. "So many people don't believe me just because I can talk. Being able to talk doesn't mean I don't have autism, it means I don't need help with speech — although sometimes I actually do."

Cami's best friend is a girl with autism who is nonspeaking. Cami enjoys many interests. "I love writing realistic fiction, anything arts and crafts, dancing, and acting. I am learning to sew and I love, love, love reading! I also love learning about Black and Latina women in history," Cami says.

She has two possible careers in mind: a performing artist or a politician. "Unless someone does it before me — which could definitely happen — I want to be the first woman president," Cami says.

If Cami's story resonates with you, learn more about what SPARK is doing to advance research of Autism Spectrum Disorder at <https://sparkforautism.org/togetherwecan> or call toll free at 1-844-54-SPARK or 1-844-547-7275.

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