

Parenting an Autistic Adult

When we talk about autism (which we are doing often during Autism Awareness Month), we tend to talk about children and ways that their parents can help. But children grow, and the parents of autistic children become parents of autistic adults, a role that is less defined and less discussed. In a guest blog today, [Laura Shumaker](#), author of “[A Regular Guy: Growing Up With Autism](#),” describes one weekend with her grown son Matthew, navigating the changing rules one interaction at a time.

THE PARTY

By LAURA SHUMAKER

When I pulled into the parking lot of my 23-year-old son’s home near Santa Cruz, Calif., he was standing there with his head cocked impatiently. “You said you would be here at 12 noon, and it’s 12:11 already,” he huffed. Even though it was a cold and drizzly February day, Matthew was wearing his favorite outfit: white socks and sandals, shorts and a Roy Orbison T-shirt.

Matthew has autism and lives at Camphill California, a community for individuals with intellectual disabilities. I was picking him up for his routine first-weekend-of-the-month visit home, an hour north near San Francisco. This weekend’s routine included a dance at our church for disabled young adults and a series of gardening jobs for neighbors and friends prearranged by Matthew himself. “He would be really good looking if he weren’t autistic,” Matthew’s younger brother once said, and while it sounded unkind, we all knew what he meant. Matthew is very handsome, with a tall and wiry frame, broad shoulders and sandy blond hair. His eyebrows arch dramatically to frame his brown eyes, and his jaw is square and masculine. But his exaggerated expressions and body carriage set him apart from the crowd. His forehead twists with intensity, he smiles too suddenly and too widely and his hungry-for-friendship gaze is desperate.

When Matthew climbed into the car for our drive home, he launched into his usual

tedious discussion about the origins of the song “Pretty Woman.”

“Who did Roy Orbison write it about? Why did Van Halen also sing the song? Was Eddie Van Halen singing it about Valerie Bertinelli? Did Roy Orbison ever get to meet David Lee Roth? Was David Lee Roth sad when Roy Orbison died?”

It is a draining conversation to maintain, but I manage to respond with feigned interest. So many of my friends have children who are nonverbal; they would give anything to have the kind of interaction I have with Matthew.

After our Roy Orbison discussion played itself out, Matthew exclaimed that he couldn't wait for the Super Bowl that Sunday.

“I didn't know you were a football fan.”

“All men are football fans,” said Matthew with a sly grin, “and they all go to Super Bowl parties.”

I felt completely unprepared for this change in the schedule, one that I knew might be hard to rig. My husband and two younger sons were away on a ski trip, and it's never easy to find and invite oneself to a party with little notice.

“I can invite some people over for the game,” I suggested.

“I want to go to a party at a different house, and I don't want my mother to be there,” Matthew replied flatly. “I'll call my friends tomorrow.”

The friends that Matthew was referring to are the nondisabled ones he knew in middle school who had been kind to him and had worked as aides in his special-education class. Most are 23, like Matthew, and have graduated from college and are in the work world. They have moved on.

When we got home, I called an army of family and friends who had generously saved the day in situations like these in the past.

“I need a Super Bowl party for Matthew,” I told them, but only one I could reach right away was my friend Kate, just as she and her family were leaving for the weekend.

“If we’re back in time Sunday,” she said, “he’s welcome to come here for sure.”

After breakfast on Saturday morning, I lingered by Matthew’s bedroom door and listened as he phoned his “friends.”

“Hi. It’s me, Matthew. Is Joe there?”

Long pause.

“When did he move?”

Pause.

“I really wanted to watch the Super Bowl with him.”

Long pause.

“O.K. Bye.”

Matthew made phone calls like this on and off throughout the day with no bites. By 4 p.m., I was counting the hours before bedtime when Matthew asked if we could go to the store.

“I want to get some chips for the Super Bowl party tomorrow. We should make some cookies, too.”

By Sunday morning, Matthew was desperate, and so was I. “I seriously need to go to a Super Bowl Party!” Matthew wailed, “and everyone is just so busy!”

I made the mistake of telling him that Kate and her family might have a party if they got home in time. Matthew jumped on the phone and called their number over and over, slamming the phone down every time he heard their “We’re not home” message.

“Would you like to go out for pizza?” I asked him. “They might be home by the time we’re finished.”

“No, thanks,” he replied, “there will be plenty to eat at the party.”

He went into his room to listen to music until 3 p.m., and then asked me for a nice plate to put the cookies on.

“I’ve decided we should just go to Kate’s house,” he said.

“That’s fine,” I replied, “but when we get there, they may not be there. Or they might be tired from their trip and tell us to go home.”

“It will be fine,” Matthew said. “I remember that they are usually really nice.”

Matthew was serene as we drove to Kate’s house, the plate of cookies and bag of chips on his lap. I, on the other hand, was a mess. Some have nightmares about going to a class unprepared — I have nightmares about imposing on people. “Please, God,” I prayed en route, “let them be home and let them invite us in.”

When we pulled up to Kate’s house, Matthew bounded up the stairs and knocked on the door with a big grin. Kate opened the door in her bathrobe and smiled back. “Matthew!” she said, “I was hoping it was you! We just got home!”

Matthew walked in and put the cookies on the coffee table just as Carrie Underwood started singing “The Star-Spangled Banner.” Kate’s husband and teenage sons took their place on the sofa next to him. “I’ll need a bowl for the chips,” Matthew said. “Mom, you’d better get going.”

Kate winked at me, I mouthed the words “Thank you and God bless you” and went home.

I dropped Matthew off the next morning at Camphill, feeling like I had just crossed the finish line of a triathlon. Before I could get away, Matthew chased after my car and

waved for me to stop.

“Mom, wait, I forgot to ask you something very important that I’ve been wondering about. Did Roy Orbison ever meet Valerie Bertinelli?”

“I don’t know,” I sighed, “but I’ll find out and we can talk about it next month.”