

*Matthew's Story:*

# *An Independent Life*

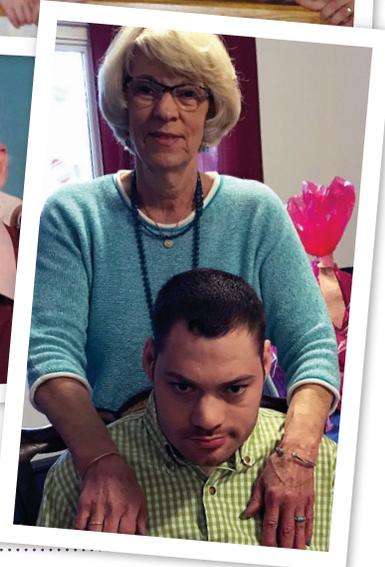
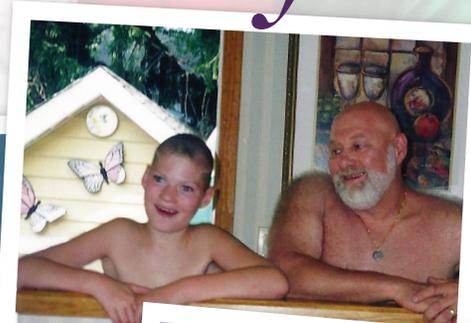


**“Most children who have Angelman Syndrome are nonverbal. I find it unbearable to realize that I will never hear my son call me ‘Mommy.’ But in my heart, I hear him talk to us every day in his own special language: Mom, Dad, I need you to know that though I cannot speak, when I look in your eyes I am telling you how much I love you.”**

**—As written by Terry, Matthew’s mother, in 1998**

Matthew is 31 years old and lives in one of Children’s Aid and Family Services’ community homes for individuals with special needs. When he was four-and-a-half years old, he was diagnosed with Angelman Syndrome, a rare chromosomal disorder that causes developmental delays and learning disabilities. “Matthew had his first seizure when he was six months old, and we knew something was wrong,” says Terry.

In the early 1990s, not much was known about Angelman Syndrome, and Matthew’s parents, Terry and Bob, went to several neurologists in search of an answer. Having a correct diagnosis enabled them to find the supports to help their son as well as themselves. “Having a strong support system is very important,” says Terry. “Our family, friends and

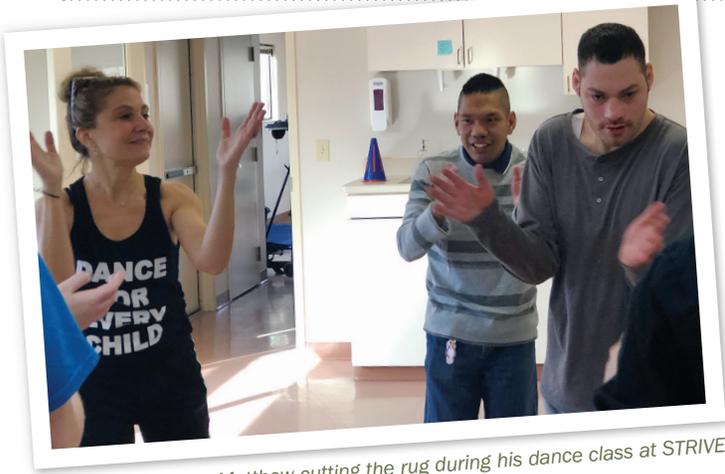


*“...this wasn’t about me and my happiness, it was about Matt’s future.”*

neighbors were very involved and helped us give Matt the best life we could.” Terry’s mother bought a hot tub for the backyard because Matt loved the water, and Bob would always make time to go in it with him, even in the middle of winter.



# CHILDREN'S AID AND FAMILY SERVICES



Matthew cutting the rug during his dance class at STRIVE.

“As a teacher with experience at all grade levels, nothing ever prepared me for parenting a child like Matthew,” says Terry. She and Bob became active in the Angelman Syndrome Foundation to learn as much as they could about his condition. They also enrolled him in early intervention and activities so he would have friends and channel his abundant energy.

## Big changes

In 2010, life took a dramatic turn for the family. Terry’s mother died and shortly after, Bob was diagnosed with cancer. Sadly, Bob passed away 13 months later, and it wasn’t long after that Terry realized she needed to find a community home in which Matthew would live. “Matt has no siblings and after Bob died, I felt like we were really on our own,” she says. “Matt needs 24/7 supervision. Our support system shrank and I knew I needed help.” She learned about Children’s Aid and Family Services from another parent. “When I found Children’s Aid, our support system grew again.”

Matthew moved into the community home on May 11, 2016. “It was the hardest day of my life,” says Terry. “But this wasn’t about me and my happiness, it was about Matt’s future.” She spends every weekend with Matthew, as well as holidays at the community home, and she has gotten to know Matt’s housemates. “They’ve become his family, too,” she says.

In addition, Matt attends the agency’s STRIVE Day Program for individuals with special needs. “Matt is energetic and he enjoys all of the activities and outings at STRIVE,” says Terry.

A gentle and happy person, Matt loves being with the staff at his community home. He lets them know when he wants macaroni salad (his favorite food), to listen to music and dance (his favorite pastime) or when he wants to watch an Adam Sandler movie on his TV (his favorite comedian). The staff works with Matt using pictures to help him enhance his communication skills and become more independent and make his own choices. “I know in my heart I made the right decision. This is his home now,” says Terry.

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*Thank You!*



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