

## Colts Neck man lives life to the fullest – his way

### Real Life Choices offers possibilities, freedom

Posted by the [Asbury Park Press](#) on 11/10/07

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When Joe Martinelli's two older sisters graduated from high school, they each had a dizzying number of decisions to make.

Would they go away to college, or stay closer to home? Which school was best for them? Which career path? Who would they choose for friends? For roommates?

The list of questions went on and on, and answering them was at once daunting and exciting, because anything seemed possible.

But when Joe, who has cerebral palsy, was still in high school, his post-graduation prospects appeared far more limited.

Many, if not most, of his classmates at the School for Children, a private school in Eatontown for developmentally disabled children and young adults ages 3 to 21, would move on to adult day programs, where they would do many of the same sorts of activities they had done in school.

"Five years ago, that would have been the (only) option my son would have had," said Joe's mother, Ann, 53, of Colts Neck. "I looked at these types of programs, and while these programs are great, they were not for Joe. I didn't want that."

Fortunately, by the time Joe, now 23, graduated in 2005, the range of possibilities had broadened considerably, thanks to a new approach toward helping individuals with disabilities and their families in New Jersey called Real Life Choices.

The approach, first introduced in New Jersey in 2003, is based on the seemingly commonsensical premise that Joe and his family know better than anyone, or any social service agency, what sort of help he needs to lead a fulfilling life.



(STAFF PHOTO: SHANNON MULLEN)  
Joe Martinelli and his mother, Ann.

Participating in Real Life Choices is optional. Individuals and families can still choose to receive assistance in the traditional manner, utilizing adult day programs, subsidized apartments and group homes, and other existing services. By opting instead for Real Life Choices, eligible participants can devise a customized support plan of their own making, funded through an annual grant from the New Jersey Department of Human Services' Division of Developmental Disabilities.

"Real Life Choices is not a program; it's part of a systems change," which New Jersey instituted at the urging of families like hers who wanted the freedom to "self-direct" their care plans, Martinelli said. "I believe it's my son's civil right to be able to choose, not to just fit into something that already exists."

What makes Real Life Choices such a major departure from the conventional approach is the wide discretion recipients have in how they utilize their annual grant allocation, which typically ranges from \$23,000 to \$64,000, depending on the level of need. For example, Bob Iannuzzi, a 51-year-old quadriplegic in Brick, has used some of his grant money to hire a personal trainer to help him lose weight and develop upper body strength so he can become more independent.

Joe Martinelli has used his grant money, the amount of which his mother preferred not to disclose, to hire his own support team.

Social services experience wasn't a big consideration; he wanted people he liked and got along with well.

"The one thing I say is that he doesn't need another mother. I do that well," Ann Martinelli said.

Joe, who lives with his parents, chose three people who are roughly his age and like to do the kinds of things he likes to do. None of them works for a social service agency. Two of them — Carrie Colbert and Brian DeLeon — have full-time jobs with the Applebee's restaurant chain, and the third person is one of his sisters, Patricia "Petie" Martinelli, 26, a special education teacher in Franklin, who often stays with Joe on weekends if their parents are away.



(PHOTO: COURTESY OF THE MARTINELLI FAMILY)  
Joe Martinelli of Colts Neck (center) is shown in the studio of Monmouth University's radio station, WCMX, with Carrie Colbert, a member of his support team (left) and Professor Aaron Ferguson, the station's faculty adviser.

Colbert arranged for Joe to work at WCMX, the campus radio station of Monmouth University in West Long Branch, every Tuesday. He also does regular volunteer work at Vonage's corporate headquarters in Holmdel as well as Prevention First, a nonprofit organization in Ocean Township that provides programming and other services targeting at-risk youth. And DeLeon takes Joe all over: to restaurants, the mall, the movies, Monmouth Park racetrack — anything Joe feels like doing.

"You are talking to a busy guy," Joe said, flashing a wry smile, during a recent interview at his family's home.

DeLeon is a pretty busy guy himself. In addition to working 50 hours per week as a senior manager at Applebee's in the Seaview Square Mall, Ocean Township, he owns a cleaning business and spends up to 15 hours a week with Joe.

The two young men get along famously, Joe's mother said.

"He likes sports, I like sports. He likes girls, I like girls. What else is there?" said DeLeon, 28, of Neptune.

"He's extremely witty," DeLeon said of Joe. "In fact he kind of surprised me, some of the things he's come up with. He's also very shy, so you have to get to know him, but once he gets going, he never stops talking."

Joe's busy and obviously enjoyable schedule wouldn't have been possible without Real Life Choices, his mother insists. She is so passionate about the self-directed approach that she has formed an advocacy group to educate more families about how it works and to lobby the state to provide more funding so Real Life Choices, which now reaches about 600 people statewide, can continue and expand. The group, called Advocates for Alternatives, Inc., held a forum in Neptune in October and plans to host a similar event sometime after Christmas, she said.

Currently, young adults with developmental disabilities automatically qualify for Real Life Choices when they turn 21, but older adults must wait up to several years until they reach the top of a long waiting list for a referral to a subsidized group home or apartment. Once an individual's name comes up, he or she can choose whether to accept the housing placement or to opt for Real Life Choices instead. The overall goal of Real Life Choices is to make it possible for more individuals with disabilities to live with their families and loved ones, who might not otherwise have the wherewithal to care for them.

The state doesn't simply write Joe a check; New Jersey has designated Easter Seals New Jersey as the "fiscal intermediary" for Real Life Choices, which makes the nonprofit agency responsible for overseeing disbursements. But as recipients become more adept and creative at seeking services, the list of eligible services keeps growing.

Social service agencies that work with the developmentally disabled can help individuals and families using Real Life Choices to coordinate the services they want or need. Still, by definition, the recipients of the grants are the ones who direct the process.

As they went about assembling Joe's support team, the Martinellis got help from the Epilepsy Foundation in crafting the help-wanted ad, but it was Joe and his family who did the interviewing and hiring.

"I'm not going to kid you — this is a lot of work, it's a lot of coordination," Ann Martinelli said. "It's not what everybody would choose to do, but it gives Joe a choice."