

Quality of Life | Two True Stories

DAVID'S STORY

Responding to care and love



Debbie Capezzuto realized, when her son David was only two, that she could no longer give him the level of care he needed. He was legally blind with numerous other

significant physical challenges and profound mental retardation.

At first she was able to place David in a special pediatric facility where he received the nursing, medical and educational supports he needed. But he eventually outgrew the program and was placed in a nursing home at age 26.

"That's when the nightmare began," she recalls. "He got no stimulation, was always jumpy, and, if you touched him, he'd react violently." And there were the numerous seizures and trips to the hospital. "The nursing home staff was afraid to touch him because he'd become so fragile. They mainly *warehoused* him."

That nightmare ended in 2005, when David moved into a small residence with specialized medical support, which he shares with seven housemates who are receiving the kind of professional care, and commitment, every person deserves.

David, now 36, has gained a healthy 14 pounds. Although his medications remain unchanged from his days in the nursing home, the seizures have ended, as have the habitual trips to the hospital.

Instead his trips consist of outings to the mall or the Cape, to church every Sunday, to the park, or to the supermarket to get the toothpaste he needs—always accompanied by trained staff who know him and know his individual needs.

A mother of four, Debbie Capezzuto recalls, "When I'd see him in the nursing home, he'd be in a room with a bunch of older people. His wheelchair would be in a corner, away from the others. But now . . . you can't imagine how wonderful David looks! How he's responded to the care and the love. It's just like *home* to him."



STEPHEN'S STORY

Enjoying family and community



Paul Tardif has two grown children. One of them, Stephen, is 47 and has lived in a community group home since he was 22. There Stephen and seven other people, who are also liv-

ing with serious, ongoing medical problems and developmental disabilities, receive the intensive medical and nursing services they need day and night.

"It's not like an institution at all," Paul says, "but more like a house . . . homelike. Other than staff being around, who'd be considered like brothers or sisters or friends, it's like a house. It's in a neighborhood."

Many years ago, Stephen's complex medical issues led to numerous recurring hospitalizations, some near fatal. But the staff in Stephen's residence have come to know him, and his conditions, intimately. The result? His last hospitalization was over 15 years ago.

"Because of his inability to speak it's hard to understand him," Paul observes. "But they know him. They're well trained and recognize when he's starting to have problems, so they react very quickly and control the problems before he gets to the point where he has to go to the hospital."



With the support of his residential staff, Stephen attends church several times a week. Paul says that Stephen, because he's a "people person," also likes helping fold church newsletters, shopping, and other community activities.

"Because of his condition, Stephen's either in his wheelchair or his bed," Paul observes. "But he's a very happy person! His biggest love of life is to see people and be with people. In a nursing home he wouldn't get out that often."

"This isn't just a quality of life issue for Stephen," he adds. "It's an issue for me. I'm in my mid-seventies now and am very comfortable with the care Stephen will get in the future. Because of this warmth he'll survive well even after my time."

Quality of Life...

We should want the best for everyone.

A good quality of life is important to us all. And when we're unfortunate enough to have serious medical problems, we want to receive the medical care we need at home or in a place that feels like home—not in an institutional setting.

Everyone deserves quality care in a homelike setting, including people with the additional challenge of developmental disabilities.

For this vulnerable population, as for all of us, quality of life means the highest possible degree of personal well-being and independence. It means being a member of a household. It means living in a safe, dignified, home setting in a neighborhood, where staff can meet medical needs and provide individual attention.

The hallmarks of institutional settings—the numbers of people, the long hallways, the insulation from everyday pleasures like meal preparation, the lack of privacy and peace and quiet—are simply not part of our picture of quality of life.



Quality of Life...

We're on our way to our goal.

Already, many individuals with developmental disabilities and complex medical needs are living in community residences and thriving because they receive not only high-level medical care but personal attention and opportunities for social growth in a homelike setting. The medical care and expertise may be the same as in health care settings and institutions, but the quality of life—for both the individuals served and their caregivers—is richer.

Massachusetts has come a long way in the past 30 years. We've provided more opportunities in the community for our citizens with developmental disabilities and complex medical needs. And we've established more homes where individuals develop close relationships and reach their fullest potential. But that's just the beginning. It's time to strengthen that trend and ensure a good quality of life for everyone. Let's move ahead together and make it happen!

Quality of Life

How do we reach our goal? Phase out institutions and build communities!

Massachusetts must make the right investments. Individuals with developmental disabilities and complex medical needs can be—and are being—cared for in the community. But Department of Mental Retardation and other disability funding has not kept pace with current needs.

Let's reach our goal by phasing out large-campus institutions, avoiding nursing home placements, and supporting home and community options.

Strengthen the trend. Ensure a good quality of life for everyone.

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Quality of Life

Living with Developmental Disabilities & Complex Medical Issues



... in the Community