

A MATTER OF PERSPECTIVE: KUCHTEY FAMILY GIVES BACK TO ONE SKY SERVICES

By Jeffrey Symes
One Sky

Like a lot of parents who provide a home and care for an adult child with a disability, Walter Kuchtey has begun to wonder if he and his wife, Becky, will be able to keep up the caregiving pace when they get older. Their 31-year old son, Matt, is blind and has cerebral palsy and while they receive support services through One Sky's self-directed program, keeping Matt active and tending to his needs is a perpetual mission.

"As a parent, I have to wonder, what's going to happen when I'm 70," Kuchtey ponders. "I'm not sure I can do this ... who knows. We like Matt to do community service and to just be out there meeting people. It's the model that New Hampshire went with many years ago."

Kuchtey is quick to point out that most of the care and advocacy for Matt has depended on the steady hand of Becky. In fact, Kuchtey spent most of his working life at sea in the Merchant Marine. Gone for 10-week stretches at a time, he admits, "it had to be difficult for the family." He retired in 2011 as a Chief Engineer with Maersk.

For his part, Matt attended the Perkins School for the Blind in Watertown, Massachusetts, for 15 years. Having that steady, reliable structure in place gave no hint at the upheaval that would come when Matt graduated. It's an open secret that the transition from school services to adult services is commonly known as "falling off the cliff" and for good reason. When a student with disabilities "ages out" of school supports at 21 and enters the world of adult services, many families



WALTER KUCHTEY WITH SON MATT, WHO IS BLIND AND SUFFERS FROM CEREBRAL PALSY. KUCHTEY SERVES ON THE BOARD OF DIRECTORS FOR ONE SKY SERVICES.

are not prepared for the day the school bus doesn't show up.

"It was an eye-opener because everything was done for you through the school and then you have to figure out what (adult) programs to do," Kuchtey recalls of that transition for Matt. The Kuchteys had chosen a vendor that provided Matt with support services for several years but staff turnover was difficult to deal with. So the family opted for a program known as Participant Directed and Managed Services (PDMS) in which the family, and not a vendor like Easter Seals or Great Bay Services, runs the program. They made the switch through One Sky Community Services about six years ago and haven't looked back.

"Running the program is a lot of work," says Kuchtey. "We decide what to do and we decide who to hire. But we chose to do it because we wanted consistency for Matt."



BECKY KUCHTEY AND HER HUSBAND WALTER ARE WONDERING HOW LONG THEY WILL BE ABLE TO CONTINUE CARING FOR THEIR SON.

Meanwhile, retirement has allowed Kuchtey to become more involved in a different aspect of Matt's supports. For the past four years, he has been one of 12 volunteers who make up the Board of Directors for One Sky. State regulations require that at least one-third of the agency's board be comprised of individuals receiving services or their family member. It's an opportunity for people with disabilities and their families to advocate for services while getting an inside look at the system charged with delivering those services.

"They're people with a lot of insight who do a lot of work," Kuchtey describes his fellow board members. "They're good people who are highly dedicated and driven."

For Kuchtey, the experience has been instructive about a complex government system and how One Sky answers to Washington, D.C. and Concord, N.H., for its work, accountable to the

federal Medicaid program and the N.H. Bureau of Developmental Services (BDS). The Portsmouth-based agency is one of 10 "area agencies" in New Hampshire designated to provide an array of services for individuals who have an acquired brain disorder or who have developmental disabilities. Arranged roughly by county, each of the agencies is a private, non-profit corporation contracted with BDS to provide services within guidelines and regulations established by the NH Department of Health and Human Services. While both state and federal dollars are invested in the system, the primary source of funding for services is Medicaid.

Between traditional budget battles and the vulnerability of Medicaid to political winds, funding for disability support services is a fickle, labyrinthine knot to untangle. "Funding, funding, funding," Kuchtey nods. "The funding is difficult. I don't get into the politics but somewhere along the line I have to know when I'm talking as a parent or as a board member. There are people (receiving services) who've had the same budget for 20 years."

For the big picture, Kuchtey would just like to get word out about the work of an agency and about efforts like a jobs initiative to get people with disabilities competitive, paying jobs. "I would like people to be aware of One Sky and what they do," Kuchtey says. "Community businesses can ease the budget concerns if they got behind it. We're trying to get as many people employed as we can."



Incorporated in 1983, One Sky Community Services has been dedicated to providing a comprehensive array of services, supports and programs to individuals and families with intellectual and developmental disabilities, as well as acquired brain disorders. A private 5013C nonprofit organization, it is the designated area agency serving the following communities: Brentwood, Deerfield, East Kingston, Epping, Exeter, Fremont, Greenland, Hampton, Hampton Falls, Kensington, Kingston, New Castle, Newfields, Newington, Newmarket, North Hampton, Northwood, Nottingham, Portsmouth, Raymond, Rye, Seabrook, South Hampton and Stratham. One Sky works with nearly 1,200 individuals and families on a yearly basis.