

LIFESTYLE / RETIREMENT

Be 'biggest advocate': Parents plan future for adult children with special needs

It's not just a matter of navigating day by day: Parents need the foresight to plan for their child's future - especially for when they will no longer be around.



Casey Lang, center, with his father, Randy, right, and stepmother, Patricia. Randy Lang sets aside weekends to spend time with Casey, who lives in a group home. Photo Credit: Howard Simmons

By Sheryl Nance-Nash

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Randy Lang looks forward to the weekend. It has nothing to do with escaping two days of work and everything to do with his 28-year-old son, Casey, who has a severe form of epilepsy and lives in a group home on Long Island. Weekends are their special time.

Lang remembers though, what it was like when Casey was a teenager.

“I was a single father. It was hard to have a career. I had to get Casey on the bus in the morning and off at 3 p.m. A lot of times he didn’t want to get on the bus, and I would have to drive him to school,” said the divorced East Northport resident, who also has an older son, Randy Jr., 32. The juggling was so stressful that by the time Casey was 16, Randy advocated vigorously with the school district to get Casey into a residential program at Maryhaven Center of Hope in Port Jefferson.

Val Pedretti, center, visits the Connetquot Public Library with her parents, Grace, left, and Paul Pedretti. The Pedretti family's weekly routine includes traveling to the library to check out books and movies for their daughter Val. Photo Credit: Johnny Milano

“I needed to be able to have a career so I could support the family and he needed to be in an environment with kids like himself and where he could learn skills to prepare for adulthood, instead of just coming home from school and being with dad,” said Lang, a labor relations professional with the New York State Nurses Association.

For the past six years, Casey has lived at the Epilepsy Foundation of Long Island’s group home in Levittown. He volunteers with Meals on Wheels and interacts as volunteer in the community with elders. On weekends Casey rides his scooter, goes boating with his family, helps his dad in the yards, hangs out with his brother.

While the family now has a rhythm, the learning curve was long. “Parents don’t know what to do. This is a whole different world,” Lang said.

If nothing quite prepares one for parenting, it’s even more daunting when a child has special needs. Parents sink or figure out how to swim in uncharted waters. It’s not just a matter of getting through day by day: Parents need the foresight to plan for their child’s future — especially for when they will no longer be around.

“As an adult child with disabilities ages, eventually they will have medical issues. Who will

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make medical decisions for them? Where will they live, who will take care of them emotionally and see to any financial needs?” asks Craig Marcott, author of “The Art of Advocacy” and a consultant with Special Needs Life Services in Melville.

There are a lot of questions and concerns that need answering.

Paul and Grace Pedretti’s 24-year-old daughter, Val, has autism. When Val was younger, the Oakdale couple said, she was a handful.

Casey Lang, right, spends time with his brother, Randy Jr., during a weekend visit with family. Photo Credit: Howard Simmons

“It took constant vigilance. We were never off, we always had to have our antenna up,” Paul said. One way they coped was by seeking out people in the same or similar situation. “Sometimes your family doesn’t understand

what you're going through because they aren't living it."

Grace chimed in, "You need a friend you can call and say, 'you won't believe what she did today.' You cry or laugh about it." Another strategy Grace offers, "red wine and chips. I would like to say yoga and meditation. I'm working on that."

For sure, it takes a village for special-needs families to not only survive, but to thrive. Think trust and estate lawyers, social workers and therapists — in addition to whatever medical professionals are necessary. Parents and guardians of special-needs children aging into adulthood need partners for the journey. Here's what they should keep in mind.

Top of must-do list

"No doubt it's overwhelming parenting a child with special needs. But we coach parents to be proactive versus reactive. Families think they have forever to plan, but you never know when you won't be able to care for them," said Charles Massimo, president of CJM Wealth Management in Deer Park, which specializes in working with special-needs families. He is also the father of two sons with autism and founder of Autism Communities, a nonprofit organization that addresses the housing crisis facing adults with autism.

Get legal help

It's best to get a lawyer who concentrates in special-needs and elder law. The law in these areas is complex and always changing.

"You want someone who specializes in these areas. They shouldn't be one of 10 areas they practice," said Stephen J. Silverberg, an estate tax and elder law attorney with the law office of Stephen J. Silverberg in Roslyn Heights. For help finding an attorney, he recommends the National Academy of Elder Law Attorneys (naela.org) and the National Elder Law Foundation (nelf.org).

Maintain control

Once a child turns 18, they are considered an adult. Parents and guardians must go through the Surrogate's Court to legally become their guardian, otherwise they will no longer have a say in their medical and other affairs. Parents should name a successor guardian, too, to take over when they can no longer serve.

Establishing a trust

Severe disabilities almost always create a significant financial burden because of the curtailed earning power of the person with disabilities (and sometimes the caregiver who is staying home to care for that person) and ongoing care-related expenses. A Special Needs Trust is a tool to help meet current needs and plan for the future. This kind of trust sets aside money and/or property for the benefit of the individual living with a disability.

Scott Pedvis, a Manhattan financial adviser with Wells Fargo Advisors explained the benefits, "It preserves eligibility for means-tested state and federal benefits and enhances quality of life by providing financial support for activities not covered by public benefits programs, such as therapy animals, accessible vehicles or supplemental caregiving services."

It's important that no money or assets are left in the child's name but are put in the trust. Money and assets in their name can affect eligibility for state and federal assistance.

Parents and guardians also need to name a trustee and a successor trustee. "Give a lot of thought to this. Is the person competent, able to manage money, organized, capable of acting on your loved one's behalf? This should not be an emotional decision," Massimo said. "The successor trustee should be just as capable." And parents should have a heart-to-heart talk with the person to make sure they are up to what will be a lifetime commitment.

Experts also recommend creating a Letter of Intent, a narrative that outlines the child's likes and dislikes, strengths and weaknesses, who their friends are and more. "This is one of the most valuable things you can do for your child, especially if they can't communicate," Massimo said.

Figure out housing

It's important to sort out housing sooner rather than later, because it can take time, even years, to find a group home.

"Have a plan for housing that may include a group home, supportive housing, relatives moving to your home or your adult child moving in with relatives," said Joan Lensky Robert, a special needs planning and elder attorney with Kassoff, Robert & Lerner in Rockville Centre.

In general, demand outstrips supply, and a range of options may be necessary over a lifetime.

Create a will

The parents' or guardians' will should leave no room for guessing. It should detail wishes and how the assets are distributed.

“Don't make the mistake of thinking equal is equitable,” Marcott said. It may not be possible to divide assets equally. For example, “If one sibling is the successor trustee, it's likely they will need a larger portion to help take care of your child. The last thing you want is friction over money, especially when you are not alive to mediate.”

And there's more ...

This list is just the beginning, experts say. Parents should also get involved with organizations that focus on the child's disability because such organizations can offer a wealth of information and support. The next step is advocacy. Many parents are propelled to fight 24/7 for their child, from the day they enter school and even after they age out of the school system at 21.

“If you're not getting answers, keep asking questions. We've had to take on insurance companies so our daughter could see specialists,” said Diane Rudman, of Manhasset Hills, who has a developmentally disabled 34-year-old daughter.

Ellen P., who lives on the South Shore but declined to provide her last name and community protect her child's privacy, went back to school to get a special-education degree to better understand the world of special needs. She and her husband have done their wills and have a Special Needs Trust in place for their son.

Ellen and her husband feel like they've covered the bases. Still she said, “It's scary to think that my son is going to have to rely on other people. Will they love him?”

The best advice, said Lang: “Keep pushing on their behalf. Leave no stone unturned. Be your child's biggest advocate.”

Resources for special-needs planning

Office for People With Developmental Disabilities (OPWDD): Information Line, 866-946-9733; opwdd.ny.gov.

Parent to Parent of New York State: 631-434-6196; parenttoparentnys.org/index.php/offices/long-island.

The Long Island Advocacy Center: 516-248-2222, 631-234-0467; theliac.org.

SILO (Suffolk Independent Living Organization): 631-880-7929; siloinc.org.

Life's WORC: 516-580-8929; lifesworc.org.

Adult & Children with Learning & Developmental Disabilities (ACLD): 516-822-0028; acld.org.

National Academy of Elder Law Attorneys: naela.org.

National Elder Law Foundation: nelf.org.

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