

Special Needs Financial Planning

Many parents face the challenge of caring for special needs children. Each child is unique and so are their families. The term “special needs” encompasses a wide variety of conditions and may mean different things to different people. The need may be medical as in cerebral palsy. It may be a physical condition such as blindness or a loss of limbs. It could be a neurological condition such as learning disabilities or autism. As different as the conditions may be, there are some common steps in planning for life and care.

GUARDIANSHIP

A guardian is a person or agency appointed by the court to make decisions and act on behalf of a person who does not have the adequate capacity to manage their own affairs. Guardianship should only be considered when less intrusive alternatives are not appropriate for the situation.

Prior to their child becoming a legal adult, parents have some control over the process. It is easier for parents to diagnose and prepare to provide for their children than it is to prove the incompetency of someone who is already an adult. This is an important consideration as a child approaches age 18 (but not before age 17 ½).

Government Benefits

Social Security Disability Insurance (SSDI) provides monthly payments to people who have a disability that makes them unable to work—for this payment, there must be a work history. Benefits may include Medicare—an automatic enrollment

two years after becoming entitled to disability benefits.

Individuals may also (or alternatively) be eligible for Supplemental Security Income (SSI) if income from other sources is below \$1,971/month. There is no requirement for a work history for SSI payments. In order to qualify for SSI, an individual’s financial resources should not exceed \$2,000. These benefits are important to help provide for care and living expenses for those who can’t provide for themselves.

ABLE ACCOUNTS

In 2014, the Achieving a Better Life Experience (ABLE) Act was signed into law. Starting in 2023, qualified individuals may save up to the gift tax exclusion amount annually (\$18,000 in 2024) in an ABLE account. Anyone may contribute to the account, but the aggregate contribution may not exceed \$18,000 and only one ABLE account may be owned at a time. This account may have up to \$100,000 without the amount being counted against the \$2,000 limit on personal assets to qualify for SSI.

These types of accounts are state-specific and established under Section 529 of the tax code. They are administered in similar ways to 529 plans for education. The funds may be used for any purpose that supports the health and well-being of the account beneficiary.

CHALLENGES

Prior to 2023, the financial challenge was to keep accumulated assets below the \$2,000 threshold for SSI benefits. With the advent of the ABLE account, that number is raised to \$100,000. In either case, getting close to the limit

requires guardians to watch their balances carefully. The funds aren’t meant to be saved, they are meant to be spent. Make sure the funds are used to support the health and well-being of the ward... and stay below the limits to continue eligibility for SSI benefits.

SPECIAL NEEDS TRUST

More funds may be saved to provide for the needs of a special needs adult through the use of a Special Needs Trust. This trust is written to ensure the assets held are not considered assets of the beneficiary. The funds may be used for the beneficiary’s health, education, maintenance, and support (HEMS). I have found that most parents tend to support their adult children with direct gifts during their lifetimes. This trust becomes very important to the beneficiary when their parents are no longer available to supplement their needs.

Choosing a trustee is vitally important in this arrangement. As mentioned above, guardians are appointed and accountable to a court. If named as trustee, a guardian may be pressured to spend funds they may not have expended under their own, independent judgement. Consider separating the guardian and trustee roles to maintain their independence and protect the financial future of the beneficiary. Make sure to choose trustworthy successor trustees to protect the interests of special needs adults throughout their lifetimes.

Special needs planning is a unique, but growing challenge for caregivers and financial professionals. Consult the appropriate professionals for tax and legal advice.



Patrick Yanke is a Raleigh-based financial advisor. Opinions expressed here are mine and not necessarily those of Raymond James. The information is not a complete summary or statement of all data necessary for making an investment decision and does not constitute a recommendation. Please consult with appropriate professionals for tax and legal issues. www.yankefinancial.com.