

# Planning for Loved Ones with Special Needs: Familial and Societal Considerations

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Parenthood is a challenging and rewarding experience. Becoming a parent of a child with special needs both enhances these experiences and presents unique circumstances. A common thread among parents is the desire to adequately provide for their children so they can achieve their maximum potential, possess self-esteem, and enjoy meaningful accomplishments throughout their lives. For parents of loved ones with special needs, obstacles to achieving such goals exist at both the family level and that of the greater community and within society. Acknowledging, understanding, and adequately preparing to manage these obstacles empowers parents as caregivers, while allowing the best chance possible for their loved ones to obtain and maintain the quality of life envisioned.

## **Family**

At the family level, a primary consideration is often how to obtain and maintain quality of life for dependents with special needs once they become adults and, typically, live very long lives. What happens when parents are no longer

able, or around, to supplement their children's needs? The solution involves being proactive to create a comprehensive, modifiable plan with built-in options based on the goals envisioned by the parents and child, while simultaneously enlisting the guidance of professionals who are well skilled in working with the families of loved ones with special needs. Goals, and the financial protection of the entire family, should be considered including any siblings without special needs and the parents themselves. When the process is executed correctly, peace of mind, a sense of empowerment, and control, often result.

The essential elements of the plan involve coordinating strategies among four areas: 1) government benefits; 2) legal; 3) care management; and 4) financial, to maximize available resources, close any gaps in supports, and maintain continuity of care.

## **Government Benefits**

It is important to maximize federal, state, and county assistance programs, while considering that government benefits only contribute to the basics of food, shelter, and clothing at or below poverty level. Medicaid is a federally run program that is administered by the states.

Supplemental Security Income (SSI) is a federally funded program that pays recipients a set monthly amount. The maximum SSI benefit is the same in all states (\$750/month as of 2018).<sup>1</sup> Both Medicaid and SSI are

needs-based programs. This means that, to qualify, an individual must have very little income and assets in their name. For most states, this threshold is \$2,000.

A significant feature of qualifying for SSI is that it automatically makes a recipient eligible, and in some states, qualified, for Medicaid. With the high-cost of healthcare, especially among those with special needs, it is important to leverage this benefit. Furthermore, receiving Medicaid is a criterion to qualify for Medicaid Waiver (Waiver) programs, which may be available after age 18. These programs help pay for healthcare services and therapies that, prior to 1991, were only available to people who were institutionalized (i.e., in a nursing facility or group home)<sup>2</sup>. Waivers allow individuals with disabilities to receive needed supports at home or at the community level. However, wait lists for waivers can be three years or more, so it is important to determine eligibility and the urgency of need as soon as possible. This can be accomplished by working with a child's case manager or supports coordinator, if assigned, and applying through the county assistance office.

## **Legal**

Special needs planning is different from general estate planning from both a legal and financial perspective. A relevant estate planning tool that can indirectly provide assets to loved ones with special needs, while allowing the maintenance of government benefits, is a Special

Needs Trust (SNT). Assets are provided indirectly by being managed through a chosen trustee or trustees. Distributions are made at the discretion of the trustee(s) for items not covered by government assistance. The SNT is generally created by parents or grandparents either during their lifetimes or at death, through their wills.

There are SNTs that can be prepared to fit various circumstances, and the common purpose is to supplement the many items not covered by government assistance programs. To ensure a proper SNT is created, it is essential to work with an attorney who is well versed in this area. Considerations include the source of the funds, whether from the individual with special needs themselves (First Party SNT) or anyone besides that individual (Third Party SNT); and when the SNT is to be funded, either while the parents are alive (Inter-vivos/Living SNT), or after they are gone (Testamentary SNT). Both living and testamentary SNTs can avail gifting by family or friends.

Pooled SNTs are a third choice, established and administered by nonprofit organizations. Joining a pooled trust can be useful for families of modest means since they do not have to pay to create an individual SNT, and/or for those who do not need a very large sum of money to be available to supplement the government benefits their child receives. Contributions of each member family are combined in a common fund, which minimizes administration and management costs. Separate accounts

are created for each individual member.

Trustee selection is a crucial decision, and often one with which many families struggle with. To assuage any concerns about appropriate use and management of funds, co-trustees may be ideal. One or more family members or friends who know the dependent well may be good choices for determining discretionary use of distributions. A professional organization, such as a bank or trust company, may be elected for their technical, accounting, and legal expertise for trust management purposes.

Further considerations for parents are decisions regarding Guardianship versus Powers of Attorney (POA) once their child turns 18 years old and is legally considered an adult. The capacity of an individual to make independent decisions and understand potential consequences, even with the support of others, is the basis of the issue. The types of decisions include those relating to healthcare and general matters, including financial. Hence, there are both Medical and General POAs. A POA is a contract between, for example, an individual with special needs and an "agent" who can guide the decision-making process and have ultimate authority.

Guardianship practices vary by state and there is no federal guideline.<sup>3,4</sup> It is a legal proceeding in which a court ultimately rules on capacity and on the appointed Guardian, taking into consideration the wishes of the

parents. Whereas POAs can be revoked should the individual have adequate capacity and make the decision to cancel the contract, Guardianship can be much more costly and difficult to terminate or to have an alternative Guardian appointed.

## **Care Management**

Aside from family members, who know the needs, goals, and best interests of their loved one, it is practical to consider enlisting the assistance of a professional care management service. The mission of these organizations is to empower and support individuals with special needs by providing customized services that improve their ability to live fulfilling lives in the community. Most provide short term, intermittent, and life-long supports including: assistance in acquiring government benefits, appropriate housing and employment; improved medical and health management, social engagement; and educational pursuits.

Once a plan is created, both legal and less formal documents can be leveraged to communicate intentions to relevant family members and professionals. A Letter or Memorandum of Intent (LOI) is a non-legally binding document that can be created by parents, and modified over time, as appropriate, to capture relevant information about their child. This tool can be used as a guide for alternative caregivers for any given time, while outlining intentions for the future. The LOI provides instructions

regarding the child's health care, education, diet, employment, living arrangements, likes, dislikes, habits, strengths, weaknesses, and goals.

## **Financial**

As primary caregivers, protecting the income earning capacity of the parents, their lifestyle, as well as their savings and retirement assets, is essential to the planning process. A proper plan can protect parental assets from being reduced or depleted, as financial demands can be immediate and overwhelming. This is worsened if one parent needs to leave the workforce to manage the needs of their child, if a caregiver is hired, or if one parent cannot face matters and leaves the family.

The quality of life of both the parents and their loved one are interdependent. This enhances the significance of having sufficient life, short- and long-term disability, as well as long term care insurance. Furthermore, raising a child with special needs often necessitates planning for a "three-person retirement," in the case of two-parent households with one dependent. In other words, long term planning strategies are essential for the financial support of two generations.

There are various methods of funding a SNT, the choices of which can have a dramatic impact on the resources ultimately available for your loved one. Considerations include the risk tolerance of the parents, interest rates,

any early withdrawal penalties, and tax consequences. Therefore, just as it is crucial to work with a specialized legal representative, it is equally important to work with a financial agent who is well versed in special needs planning.

Determining the amount of assets ultimately needed to fund a SNT can be estimated based on variables such as the diagnosis, prognosis, functional skill level, anticipated housing situation, earning potential, healthcare needs, and cost of other necessary supports throughout adulthood. A competent financial specialist can help in determining a targeted sum, and in reviewing beneficiary designations of accounts such as retirement plans and life insurance policies.

The age that a parent begins to elect Social Security benefits is a further consideration. The earlier Social Security begins for a parent, the greater the lifetime disability benefits are reduced for their child with special needs. This is because the benefit increases each year one waits to claim it up to age 70. A child can get social security benefits from a parent that retires, dies, or becomes disabled at any age, provided the child themselves is deemed disabled prior to age 22 and remains so.

## **Society**

At the societal level, considerations include community

integration via meaningful employment and appropriate housing options to facilitate maximum independence. There are ongoing efforts among academic, nonprofit, corporate, and parent-based organizations to create opportunities while providing incentives to employers and real estate investors. Individuals who have direct experience supporting the special needs community, and others who have either congenital or acquired disabilities themselves, are creating and leveraging technological innovations, including various apps, that can support independence and inclusion of those with special needs in the community.

Some apps are available, and others are in development to support real-time tracking, live connections, and communication among individuals, parents, caregivers, and employers. Many such apps can be customized to prompt individuals to complete tasks in the home or workplace, while notifying a caregiver or employer of the outcome. It is possible for dynamic changes and updates to be automatically captured in some instances without being pre-programmed. Such "machine learning" can facilitate real time care management, for example, based on needs as outlined in an Individualized Support Plan (ISP)<sup>5</sup>.

## **Author bio**



*Photo Credit: Marianne Walls Photography*

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As a Financial Agent and mother of a child with a cognitive disability, Lori helps parents navigate through the special needs planning process. This includes assisting them to secure the future they envision for themselves and all family members by ensuring financial, legal, and government benefit resources effectively combine to work to their advantage.

<sup>1</sup> Social Security Administration at [www.ssa.gov](http://www.ssa.gov) for 2018.

<sup>2</sup> Nursing and Behavioral Health Services at [www.nbhslic.com](http://www.nbhslic.com).

<sup>3</sup> Check with state laws to ensure that Guardianship is applicable.

<sup>4</sup> Annual Practices Update on Guardianship Laws and Practices at [www.ncler.acl.gov](http://www.ncler.acl.gov).

<sup>5</sup> Analytics Software and Solutions at [www.sas.com](http://www.sas.com).