



PLANNING FOR YOUR CHILD
WITH SPECIAL NEEDS
Guide

RUSSO LAW GROUP, P.C.

Estate Planning, Elder Law & Special Needs



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What Every Parent who has a Child with Special Needs Should Know about Estate Planning

Planning for Your Child of Any Age

Regardless of your child's age or special need, as a parent you want nothing more than to make sure you are doing everything to love, nurture, protect and provide for your child. From the moment your eyes first meet, you experience a flood of emotions – hope, love, fear – emotions that envelop your every thought. You wonder, “Who will they be when they grow up?” “Will I make the right decisions?” “Am I prepared for this life-long journey?” And “Who will care for my child if I am no longer here?”

Where do you begin? You develop a plan.

Do not think of this as planning for your demise, but rather a life plan for your child. There are three key elements to consider: Memorandum of Intent, Decision Making and Government Benefits. Chronological age means little for children with special needs. Young or old, the need for special care continues.

A **Memorandum of Intent** is a personal letter from you to the people who will care for your child when you no longer can.

It is also important to provide for your ongoing financial, healthcare, and personal decision making by designating an agent to make decisions for you if you are not able to yourself. A **Durable Power of Attorney** allows a trusted person, typically a family member, to be able to make financial decisions and to manage and protect your assets and a **Health Care Proxy** allows you to appoint an agent to make health care decisions for you if you are not able to yourself.

Supplemental Security Income (SSI) and **Medicaid** are two important Government Benefit Programs that provide funds, medical care, and services for children with special needs. SSI provides a monthly stipend to help pay for living expenses and Medicaid can take care of the medical services, including therapies and care at home. The NYS Office for People with Developmental Disabilities (OPWDD) is the governmental agency that oversees the valuable services provided to individuals with special needs, including services under Medicaid waiver programs.

Parents of a child with special needs can use their own funds to create a **Supplemental Needs Trust** that will not affect the child's eligibility for any of these government programs. If the person with special needs has assets, then a **Special Needs Trust** can be used to protect them.

It is critical to take steps now to protect your child with special needs. Regardless of your child's age, the legal documents discussed above can ensure that your child has the best quality of life. Isn't that what we want for all of our children?

Planning for Your Child with Special Needs at Age 14

Every child has needs – a need to be loved, encouraged, and cared for. This is the most joyful and daunting of experiences a parent will ever know. Unfortunately, a parent handbook is not one of the items included in a “goodie bag” once you leave the hospital after the birth of your child. Every child is special – that first birthday, school moving-up ceremony and, of course, the crossover from pre- to teenage years.

As parents of a special needs child, it is important that your planning for that child grows with their needs. When your child reaches age 14, it is a suitable time to review the planning that you have in place for your child. You should review and update the **Memorandum of Intent** which provides guidance to those who may have to help in the event of an emergency. You should also make sure that you have nominated a legal guardian for your child under your Will.

Supplemental Security Income (SSI) Eligibility

SSI is a **Government Benefit** program, administered by the Social Security Administration, which can provide a monthly stipend to your child once they are eligible. This monthly stipend provides your child funds to meet basic needs for food, clothing, and shelter. SSI has strict eligibility rules. Typically, eligibility is available at age 18 because the deeming of the parents’ income and assets is cut off at that time.

If your child is age 14, it is a suitable time to review the SSI eligibility rules. SSI has a three year look back period from the date of application to review all financial transactions of the applicant. Three years from now, your child will be 17 so it is not too soon to start a financial review to help assure eligibility for SSI at age 18. Remember that SSI also has a resource limit of \$2,000. Now is the time to make sure that your child at age 14 will qualify for SSI upon reaching age 18.

Last Will and Testament

You should also review your current Will to ensure you are still comfortable with your choice of guardian for your child as well as with the way you have chosen to distribute your assets upon your demise.

Supplemental Needs Trust

Parents can establish a **Supplemental Needs Trust** for the benefit of their child without adversely affecting their child’s eligibility for government programs such as SSI and Medicaid. This trust can be established under a Will or by a Trust set up during their lifetime.

Special Needs Trusts

A **Special Needs Trust** can be funded with the assets of your child and then used for their benefit without adversely affecting SSI and Medicaid benefits. Certain requirements must be met. The State is entitled to be reimbursed for all Medicaid provided from any remaining trust assets when your child passes away. Another alternative is a **Pooled Special Needs Trust** established by a charity.

Able Accounts

An Able Account may be established for the benefit of a person who was determined to be disabled prior to age 26. The funds can be used to improve the health, independence, or quality of life of the person while maintaining eligibility for Medicaid and SSI benefits. Many families supplement their child's special needs trust with an ABLE account because funds from the ABLE account, used for food and shelter, do not affect the child's SSI income.

Planning for Your Child with Special Needs at Age 18

A parent of a child with special needs makes personal, financial and health care decisions for the child on a continuing basis from birth. It is difficult for a parent to accept that upon a child attaining age 18, the parent loses the authority to continue making decisions for their child, even though the child may not have the ability or capacity to do so.

Decision Making – Guardianship

At that time, the parents should commence a guardianship proceeding (typically in the County Surrogate's Court) when the child reaches age 17½. The parent can be designated as the child's guardian, but it is also recommended that the parent select a standby guardian who would be authorized to act in the event the parent is unable to do so.

As guardian, the parent or standby would be empowered to continue making the decisions for the child without regard to age. Additionally, the parent/guardian would be authorized to make end of life decisions for the child with disabilities, because of the law adopted by New York State. A less restrictive alternative to a guardianship proceeding may be a Supported Decision Making agreement entered into between the adult child and the parents as the supporters to assist the adult child in decision making.

Sometimes an adult child with special needs may be able to sign advance directives, including a durable power of attorney and health care proxy, and avoid the need for a guardianship.

SSI Eligibility

This is the appropriate time to consider applying for SSI. Under the eligibility rules, SSI considers a child 18 years or older to no longer be affected by a parent's assets and can be eligible on his/her own account. If the parent provides food or room and board, the child's SSI grant can be reduced by up to one third (1/3). Parents must keep the child's assets below \$2,000 for SSI eligibility. The use of Special Needs Trusts or an Able Account can protect assets enabling your child to be eligible for SSI benefits.

Supplemental Needs Trust

The parents should consider updating their Supplemental Needs Trust (see above). This trust, when properly drawn, can supplement and enrich the child's life without affecting SSI or Medicaid eligibility. Other people seeking to help the child financially can also contribute to the Supplemental Needs Trust.

Planning for Your Child with Special Needs at Age 21 or Older

Let us circle back to when you realized that your child had special needs - the flood of emotions, the questions. You know the meaning of "milestones" - first birthday, becoming a teenager, entering adulthood. Now, your "child" has turned 21. You may not be legally responsible for your child; however, "legal" responsibility was never your motivation in the first place. Yes, adulthood is here, however the care required for your special needs child continues. You are not alone on your journey. Continued planning is the key.

OPWDD

The NYS Office of People with Developmental Disabilities ("OPWDD") is responsible for coordinating services for people with developmental disabilities including intellectual disabilities, cerebral palsy, down syndrome, autism spectrum disorders, Prader-Willi syndrome, and other neurological impairments. It provides services directly and through a network of approximately 500 nonprofit service providing agencies, with about 80 percent of services provided by the private nonprofits and 20 percent provided by state-run services.

Medicaid

At 21, your child can now be Medicaid eligible without regard to the income or assets of the parent. Only if you give these to your child will you affect their own eligibility. Medicaid's home care program can provide some respite. A personal care aid paid for by Medicaid can perform many of the chores including bathing, toileting, and dressing, which would otherwise be performed by the parent. Prior to age 21, your child may qualify for Medicaid under a "waiver program".

Housing

At age 21, your child may remain home or may benefit from housing options outside of your home. A group home or supportive housing can offer the possibility of living with others of a similar age, offering experiences not available when living with you. Another option could be independent living in an apartment-type setting with assistance, if appropriate. Rent assistance is available from the Federal government through the Section 8 program.

“Ticket to Work,” “Trial Work” and “Pass” Programs

The “Ticket to Work” program is the most flexible and is available to those receiving social security disability benefits or SSI. Administered by the Social Security Administration, your child receives a “ticket” that offers access to various New York State vocational and rehabilitation agencies.

Both the “Trial Work” and “Pass” (Plan for Achieving Self Support) programs require continuing disability reviews which can result in your child being dropped from Social Security Disability or SSI. This cannot happen if your child is in the “Ticket to Work” program. As long as your child is enrolled in “Ticket to Work,” there is no continuing disability review. Your child can be in this program for up to 3 years, during which time there is no possibility that they will no longer be considered disabled because of employment.

Remember that you are ageing with your child and, as such, needs and circumstances change. This is a good time to review and update your Memorandum of Intent. Also, it is important your own estate plan is up to date.

Take steps now to protect your child with special needs. Contact us for a planning meeting today!

Russo Law Group, P.C. advocates for and represents seniors and people with special needs and their families. Call us on (516) 683-1717 or visit us at www.VJRussoLaw.com for more information.

NOTE: This guide is merely informational and not legal advice. This guide was published in January 2025 and based on New York law. You should contact us about any changes or updates in the law or if you have any questions regarding the planning strategies that make sense for you. Future changes in law may render the above information inaccurate.

If you have any questions regarding this guide, please do not hesitate to call RUSSO LAW GROUP, P.C. at (516) 683-1717 or contact us at www.VJRussoLaw.com.

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