

**SPECIAL NEEDS PLANNING
BY AGE**

***PLANNING FOR YOUR CHILD
WITH SPECIAL NEEDS***

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

This is the first part of a four part series on estate planning for parents who have a child with special needs.

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 will 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. 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** contains instructions to a future guardian or caretaker provided by you the parent – discipline, your child's preferences for entertainment, friends, groups or clubs. You can identify all of your relatives and list the names and addresses of physicians, schools, counselors and attorneys. Think of it as a road map to the life of your child. This could enable the guardian or caretaker to make a more meaningful and beneficial contribution, if the need arises.

Detail your financial, healthcare and personal decisions and designate an “agent” to make your financial decisions with Advance Directives such as a Durable **Power of Attorney and Health Care Proxy**. 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 if you are not able to yourself.

Medicaid and SSI are two important **Government Benefit** programs that provide 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 Office of Mental Retardation and Developmental Disabilities (OMRDD) 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?

Growing With Your Special Needs Child Age 14

Every child has needs – a need to be loved, encouraged and cared for. This is probably 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 step-up ceremony and of course, the cross-over 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 of 14, it is a good 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 he or she is eligible. This monthly stipend allows your child funds to meet basic needs for food, clothing and shelter. SSI has very 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. It is a good idea at age 14 to start to think about SSI.

If your child is age 14, it is a good time to review the SSI eligibility rules. SSI has a three year look behind the date of application to review all financial transactions of the applicant (the “three year look back period”). 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.

Will: 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’ve chosen to distribute your assets upon your demise. Parents can fund a **Supplemental Needs Trust under their Will** for the benefit of the child without adversely affecting the child’s eligibility for government programs such as SSI and Medicaid.

Here Comes the Sun Guidelines for Parents with a Seventeen Year Old Child with Special Needs

A parent of a child with special needs has been making personal, financial and health care decisions for the child on a continuing basis since birth. It is difficult for a parent to accept that the child's birthday will limit the parent's authority to continue making the child's decisions, knowing that the child's ability or capacity will not suddenly increase because of a birthday.

Decision Making – Guardianship

Accepting the reality of the age situation, the parent should commence a guardianship proceeding in the Supreme Court. 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 "child's" decision's without regard to age. Additionally, the parent/guardian would be authorized to make end of life decisions for the "child" with disabilities, as a result of the law adopted by New York State.

SSI Eligibility

This is the appropriate time to start planning for the "child's" SSI eligibility. SSI considers a "child" 18 years or older, no longer affected by a parent's assets, and can be eligible on his/her own account. If the parent provides room and board the "child's" SSI grant can be reduced by one third (1/3). Parent should keep the "child's" assets below \$2,000.00 for SSI eligibility.

Special Needs Trust

The parent should consider establishing a special needs trust. This trust when properly drawn can supplement and enrich the "child's" life without affecting SSI eligibility. Other people seeking to help the "child" financially can also contribute to the special needs trust.

Guidelines for Parents with a 21 Year Old “Child” with Special Needs

Let's circle back to my first article in this four-part series, *What Every Parent Who Has A Child with Special Needs Should Know About Estate Planning* - 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 in your journey. Continued planning is the key.

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, dressing, that would otherwise be performed by the parent.

Housing - At age 21, your child could benefit from housing options outside of your home. A group home can offer the possibility of living with others of a similar age, offering experiences not available when living with you. Or, independent living in an apartment type of setting could be an appropriate option. Rent assistance is available from the Federal government through the section 8 program, and also from the local department of social services.

Job – “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 Administrator, 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 he or she will no longer be considered disabled because of employment.

Remember that you are aging with your child and as such, needs and circumstances change. This is a good time to review and update your Memorandum of Intent.

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

Vincent J. Russo & Associates, P.C. advocates for and represents seniors and people with special needs and their families. Visit us at www.VJRussoLaw.com for more information.

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