

Life Planning for Families with Special Needs

Adrienne Arkontaky, Esq.
Vice President/Managing Attorney
and Gina Sinon, Esq.



50 Main Street, Suite 1280
White Plains, New York 10606

T: 914-984-2740 - F: 914-449-1613

www.cuddylawfirm.com

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Important Questions



- Who will care for my child when I am gone?
- Where will my child live?
- Who will make certain that he or she receives proper medical attention?
- Who will manage my child's care
- Who will make educational decisions for my child?
- Will there be enough money to provide for a good quality of life for my child?

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Life Planning

Includes a well-thought out plan so that everyone involved in your child's care recognizes his or her needs. Developing this plan will allow families to provide the best quality of life possible and assist a child to develop to his or her fullest potential with all the support necessary.



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What does the Life Plan Consider?

- The child's medical, behavioral, social, emotional, educational, vocational needs
- The family's assessment of the child's needs and their hopes for the future
- An assessment of the financial commitment necessary to provide the child with the proper amount of care and support.

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Other Important Considerations

- A child with special needs might never be capable of self-support
- The need for care may be life long
- Government benefits and supports might not be available long term
- What are the capabilities of the child?



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Possible Actions



- Do nothing and hope for the best-NO
- Rely solely on government benefits-NO
- Develop a Life Plan-YES
- Put together a team of professionals to assist in the development of a LP-YES
- Review Estate Plan including the need for a SPECIAL NEEDS TRUST-YES, YES
- Get your own house in order-huh?

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The Life Plan Components



- A Letter of Intent
- A well-thought out Estate Plan
- A Team approach to planning-The family, a special needs lawyer, a financial planner
- REVIEW PLANNING ON A REGULAR BASIS
- Hold a team meeting AND
- Remember to involve the child if possible!

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Special Needs Estate Planning

- Review the need for a Will with a Special Needs Trust.
- Decide who will be the Executor, Trustee and Guardian of your minor children.
- Make sure everyone eighteen and older has **advance directives** OR a guardianship in place.

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The Letter of Intent

Letter of Intent is a non-legally binding document consisting of the caregiver's intentions for the child

- Communicates the needs of the child and desires of the family and provides a "guidepost" to future caregivers
- The "Letter" can be in any form you desire- audio, video, written etc.
- Review and revise it regularly

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The Team Approach

- Family members
- The child
- Future care/advocacy organization
- Financial planner or insurance agent
- Lawyer
- Accountant



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Advocacy

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Be sure there is always an advocate for your child

- An individual, often a parent, sibling or relative who is familiar with the needs of the child
- Review evaluations, IEP's, ISP's and medical information in order to make informed decisions
- Make sure the advocates have copies of all life planning documents




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Guardianship

Guardian of the Person

Vs.

Guardian of the Property



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Appointing the Guardian

- The petition
- The hearing
- Periodic accounting and reports

Continued court involvement provides added protection to the child and the guardian

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Funding A Life Care Plan

- The use of life insurance
- Re-titling assets-very important!

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Government Benefits

Social Security
Social Security Disability
Medicare
VS.

Means-based programs
Supplemental Security Income
Medicaid

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SPECIAL NEEDS TRUSTS

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Self-Settled Special Needs Trusts

- Created with the child's own assets
- Must contain a "payback" provision
- Must be established a by a parent, grandparent, guardian or by court order



Supplemental Needs Trusts-3RD Party Trusts

- Hold assets for the benefit of a child with special needs
 - Lifetime trust
 - Will
- Provide a "supplemental" source of funds without jeopardizing Medicaid eligibility
- Contain certain limitations on the use of trust property
- A non-countable asset for Medicaid eligibility purposes
- No payback provision

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Pooled Trusts

- Established with the child's own assets
- Managed by a non-profit organization
- Assets are pooled for investment and management purposes only
- Modified payback provision

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Conclusion

- Every child is unique
- Plan early and review plan on a regular basis
- Look for team players who are familiar with children with special needs
- Once the planning is done, relax and have peace of mind.....

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The End



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PLANNING FOR THE FUTURE

If you have a loved one with disabilities, you want to do as much for them as possible. This includes planning for their future once you can no longer take care of them. Thankfully, we can help you prepare and develop a lifetime plan of care.

Our special needs planning attorneys will work with your family to create a plan customized for your loved one with disabilities. The plan may include:

- Assistance with estate planning,
- Preparation of special needs trusts,
- Preparation of advance directives,
- Guardianships, and
- Access to government benefits such as Medicaid and OPWDD eligibility.

KNOW YOUR CHILD'S RIGHTS

Your child is your life. But what happens when your child with special needs isn't progressing in reading? What happens when the school district decides to take services away from your child? What happens when the school isn't following your child's Individualized Education Program (IEP)?

By law, your child with special needs is entitled to appropriate educational services. If the school district makes decisions you don't agree with, you can get help from a special education attorney.

The Cuddy Law Firm focuses on special education law and has empowered thousands of New York parents. Parents, trust your instincts — if you think your child is not receiving an appropriate education, let us help. Contact us today for a consultation.

The Cuddy Law Firm, PLLC is dedicated to serving individuals with disabilities and their families in the areas of:

- Special Education Advocacy and Litigation
- Special Needs Estate Planning
- Special Needs Trust Administration
- Guardianship
- OPWDD Appeals
- Medicaid Appeals
- Estate Administration

WESTCHESTER OFFICE

50 Main Street, Suite 1280
White Plains, New York 10606
P: 914-984-2740

AUBURN OFFICE

5693 South Street Road
Auburn, New York 13021
P: 315-370-4020

www.cuddylawfirm.com

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50 Main Street, Suite 1280
White Plains, New York 10606
P: 914-984-2740
F: 914-449-1613

AUBURN OFFICE

5693 South Street Road
Auburn, New York 13021
P: 315-370-4020
F: 718-569-6466

www.cuddylawfirm.com

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MEET THE WHITE PLAINS TEAM

Adrienne J. Arkontaky is the Vice President and Managing Attorney of the White Plains Office with The Cuddy Law Firm. Adrienne's practice focuses on special needs planning, special education advocacy and litigation and guardianship for families of children with disabilities. Adrienne is a member of the Committee on Issues Affecting Persons with Disabilities for the New York State Bar Association and the Co-Chairperson of the Special Education Committee of the NYSEA and Lawyering and Parenting Committee of the Westchester Women's Bar Association. She is also the parent of a young adult with severe disabilities.

Kerry McGrath is an attorney in the White Plains office. Kerry focuses her practice on special education advocacy and litigation and guardianship. She graduated from New York Law School. Kerry graduated *magna cum laude* from Syracuse University, Maxwell School of Public Citizenship. She is a member of the Phi Beta Kappa National Honor Society. Prior to law school, Kerry was a New York City public school teacher. She participated in the New York City Teaching Fellows program and taught fifth, sixth, and seventh grade English as a Second Language (ESL) at Intermediate School 52. She also earned a Master's degree in Education at City College of New York.

Katherine Aquino-Meleendez is an attorney in the White Plains office. Katherine graduated *magna cum laude* from Florida International University and received her Juris Doctorate degree from Hofstra University School of Law. While in law school she was an active member of LALSA (Latino Law Student Association) and a member of the Student Bar Association. She is admitted to practice in New York and is fluent in Spanish. Her practice focuses on special education litigation.

Gina M. Sinon is an attorney in the White Plains office. Gina is experienced in all types of estate planning, and guardianships, including planning for families with loved ones with special needs. Gina was admitted to the Bar in 1993 and began her practice at a large Manhattan firm before transitioning to a smaller firm and focusing on estate planning. She brings a wide range of experience to The Cuddy Law Firm from estate planning to litigation, real estate and corporate law, which all assist in the development of a unique estate plan for each individual client.

Andrew Weisfeld is an attorney in the White Plains office. Andrew received a Juris Doctor degree from Fordham University School of Law. While at Fordham, Andrew was a competitor and business editor for the Brendon Moore trial advocacy program, Associate Editor for the Fordham Urban Law Journal, and recipient of the Archibald R. Murray Public Service Magna Cum Laude award. During this time Andrew interned in the Family Law Unit of the New York Legal Assistance Group, interned for the Honorable Judge John P. Colangelo in the New York State Supreme Court Post-Matrimonial division and litigated Special Education cases as a participant in the Lincoln Square Legal Services Family Advocacy Clinic.

Carmen Perez-Barton is the White Plains Office Manager and a bilingual (Spanish) paralegal. Carmen graduated from the College of Mt. St. Vincent with a degree in finance. She is available to assist our Spanish-speaking families navigate the very complex world of special education. Carmen also assists our clients with our trust administration clients.

Margaret Vogt is a special education paralegal with The Cuddy Law Firm. Margaret has over twenty years experience assisting families in advocating for loved ones with disabilities. Margaret received her Bachelor of Art degree from Brown University and her Masters degree from the Fletcher School of Law and Diplomacy. Margaret served as Chairperson of the Commissioner's Advisory Panel of the New York State Department of Education and she was a long-standing member of the Office of Persons with Developmental Disabilities (OPWDD) Commissioner's Advisory Panel. Margaret is the parent of a young adult with special needs.

Theresa Cierniecki is a litigation paralegal who is trained in both civil and criminal law. She has a great interest in special education advocacy and has four years of experience as a special education paralegal. Prior to working as a special education paralegal, she was the head paralegal of the Criminal Court Bureau at the office of the Bronx District Attorney where she contributed in the prosecution of misdemeanors including crimes against victims. While there, Theresa managed nine other paralegals in preparing Assistant District Attorneys in responding to discovery requests and preparing for trial.

Amanda Ford is a paralegal in our White Plains Office. She provides support for our clients and attorneys, focusing on all special needs planning matters including estate planning and guardianship proceedings. She is also our firm development coordinator assisting with most of the marketing ventures.

Daisy Cruz is an administrative assistant in our White Plains Office. She is bilingual (Spanish) and being the first point of contact she handles all intakes for our White Plains Office.

Achieving a Better Life Experience (ABLE) Act

Division B of Public Law 113-295, December 19, 2014



OVERVIEW

The Stephen Beck, Jr., Achieving a Better Life Experience Act¹ (ABLE) Act was signed into law on December 19, 2014 after many years of advocacy and bipartisan work in both the House and Senate. The law allows eligible individuals with disabilities the ability to establish “ABLE accounts” for qualified beneficiaries that resemble the qualified tuition programs, often called “529 accounts”, that have been established under that section of the tax code since 1996. The new ABLE accounts will allow more individual choice and control over spending on qualified disability expenses and limited investment decisions, while protecting eligibility for Medicaid, Supplemental Security Income, and other important federal benefits for people with disabilities. Without these accounts, many people with disabilities have very limited avenues to save and allow for further independence.

A Form of 529 Account: The ABLE Act creates a new Section 529A establishing new tax-favored Qualified ABLE Programs in the Internal Revenue Code. The ABLE Program accounts are intended to be easy to open and available in any state, although each state will need to take action to make the accounts available to its residents. Assets in an ABLE account and distributions from the account for qualifying expenses would be disregarded or receive special treatment when determining the beneficiary's eligibility for most federal means-tested benefits.

Key Characteristics of ABLE Accounts:

- An eligible individual may have **one ABLE account**, which must be established in the state in which he resides (or in a state that provides ABLE account services for his home state).
- Any person, such as a family member, friend, or the person with a disability, may contribute to an ABLE account for an eligible beneficiary.
- An ABLE account may not receive **annual contributions** exceeding the annual gift-tax exemption (\$14,000 in 2015). A state must also ensure that aggregate contributions to an ABLE account do not exceed the state-based limits for 529 accounts.
- **Eligibility** - An eligible individual is a person (1) who is entitled to benefits on the basis of disability or blindness under the Supplemental Security Income (SSI) program or under the Social Security disability, retirement, and survivors program OR (2) who submits certification that meets the criteria for a disability certification (to be further defined in regulations). An eligible individual's disability must have occurred before the age 26.
- **Designated Beneficiary** - The eligible individual who established the ABLE account and who is the owner of the account is the “designated beneficiary”.
- **Qualified disability expenses** are any expenses made for the benefit of the designated beneficiary and related to his/her disability, including: education, housing,

¹ After Stephen Beck's death in December 2014, the law was named to honor him, a parent from northern Virginia who helped conceive and develop the ABLE Act and who worked tirelessly for its passage.

transportation, employment training and support, assistive technology and personal support services, health, prevention and wellness, financial management and administrative services, legal fees, expenses for oversight and monitoring, funeral and burial expenses, and other expenses, which are approved by the Secretary of the Treasury under regulations.

- **Tax treatment** - Earnings on an ABLE account and distributions from the account for qualified disability expenses do not count as taxable income of the contributor or the eligible beneficiary. Contributions to an ABLE account must be made in cash from the contributor's after-tax income.
- **Roll-Overs** - Assets in an ABLE account may be rolled over without penalty into another ABLE account for either the designated beneficiary (for instance, when moving to another state) or any of the beneficiary's qualifying family members.

Federal Treatment of ABLE Account Under Means-Tested Programs, Including Supplemental Security Income & Medicaid:

- **Means-Tested Programs generally** - Assets in an ABLE account and distributions from the account for qualified disability expenses would be disregarded when determining the designated beneficiary's eligibility for most federal means-tested benefits.
- **Supplemental Security Income (SSI):** For SSI, only the first \$100,000 in an ABLE account will be disregarded. Assets above \$100,000 will count as resources under SSI. In addition, if the designated beneficiary's ABLE account balance exceeds \$100,000, the individual's SSI benefits will not be terminated, but instead will be suspended until such time as the individual's resources fall below \$100,000. Further, it is intended that distributions expended for housing purposes will receive the same treatment which all housing costs paid by outside sources receive.
- **Medicaid Eligibility:** A beneficiary will not lose eligibility for Medicaid based on the assets held in their ABLE account, even during the time that SSI benefits are suspended (as described above for an account with over \$100,000).
- **Medicaid Payback Provision:** Subject to certain limits and upon the state's filing of a claim for payment, any assets remaining in an ABLE account upon the death of the qualified beneficiary must be used to reimburse the state for Medicaid payments it made on behalf of the beneficiary. The amount of any Medicaid payback is calculated based on amounts paid by Medicaid after the creation of the ABLE Account and shall exclude amounts paid by the beneficiary as premiums to a Medicaid buy-in program.

How Soon Will ABLE Accounts Be Available?

- **Federal Regulations:** The Secretary of the Treasury is required to issue regulations or other necessary guidance within six months of enactment of the law, which would require such regulations and/or guidance to be available by mid-June 2015.
- **State Decisions:** Each state will need to decide whether to offer a qualified ABLE program to its residents, and, if so, the state will need to decide whether the program will be state-run; whether to select another entity, such as a financial services firm, to run the program; or whether to contract with another state to allow its own residents to use the qualified ABLE program of another state.



Adrienne Arkontaky, Esq.

VICE PRESIDENT/MANAGING ATTORNEY

Email: aarkontaky@cuddylawfirm.com

Direct Phone: (914) 984-2741

Adrienne J. Arkontaky is the Firm's Vice President and Managing Attorney of the White Plains office. Adrienne's practice focuses on special education advocacy and litigation, special needs estate planning including special needs trust administration and litigation, guardianship, Medicaid, OPWDD and other administrative appeals.

Adrienne has been instrumental in assisting families throughout the state obtain appropriate educational services for children with special needs and plan for the future by setting up proper special needs estate planning and assisting families with special needs trust administration issues. Adrienne previously served as the Pro Bono Coordinator for a major law firm and a Medicaid Service Coordinator for Family Connection, an agency providing case management for families of children with disabilities. Adrienne received her Juris Doctor degree from Pace University School of Law and received her Bachelor of Science degree in Business Administration from Iona College.

Adrienne is the Chairperson of the Special Education Committee and a member of the Special Needs Planning Committee of the Elder Law and Special Needs Section of the New York State Bar Association, a Past Co-Editor of the Elder Law and Special Needs Law Journal, Co-Chair of the Education Committee and Past Co-Chair of the Lawyering and Parenting Committee for the Westchester Women's Bar Association. Adrienne is also a member of the Disability Rights Committee for the New York State Bar. She was named "A Rising Star" in Super Lawyers 2013 and one of the Top Attorneys in the Metro Region for 2014 and 2015.

Adrienne serves as the Chairperson for the Board of the John A. Coleman School, with campuses in New York City and White Plains. She is a member of the Council of Parent Advocates and Attorneys (COPAA). Adrienne lectures frequently to advocacy groups and other professional organizations on special needs planning and the importance of understanding special education laws.

Adrienne lives in Hawthorne with her husband, Peter and 3 children. She is the parent of a special needs adult child living at the Center for Discovery.



Gina M. Sinon

Email: gsinon@cuddylawfirm.com

Direct Phone: (914) 517-9553

Gina M. Sinon is an attorney in the White Plains office. Gina is experienced in all types of estate planning and guardianships, including planning for families with loved ones with special needs.

Gina graduated *cum laude* from Fordham University School of Law and a member of the Order of the Coif, a legal honor society. She received a B.A. from Washington University in St. Louis, with a major in History and a minor in Italian.

Gina was admitted to the Bar in 1993 and began her practice at a large Manhattan firm before transitioning to a smaller firm and focusing on estate planning. She brings a wide range of experience to The Cuddy Law Firm from estate planning to litigation, and assists her clients in the development of a unique estate plan for each individual client.

Gina lives in Westchester with her husband and three children.