

**PLANNING FOR THE FUTURE**

**A GUIDE FOR FAMILIES AND FRIENDS  
OF PEOPLE WITH DEVELOPMENTAL  
DISABILITIES**

**2006  
6<sup>th</sup> Edition**

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## **Special Organizational Acknowledgement**

Disabled and Alone Life Services for the Handicapped, Inc.

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## MESSAGE FROM THE NEW YORK STATE DEVELOPMENTAL DISABILITIES PLANNING COUNCIL

Most families provide lifelong supports to their family members with a developmental disability. However, if you are like most families you have not planned very far into the future. In fact, seventy-five percent of families with a daughter/son with a disability never plan at all.

We would like to change that.

Planning is a good thing to do. Making plans can relieve much of the emotional and economic strain of caring for someone. Ultimately, it frees the family to tend to the important details of living and nurturing the family member with disabilities. You also gain a sense of reassurance in knowing that your family member will receive necessary supports long after you are unable to provide those supports.

Long term care planning for your family member with disabilities means planning for his/her adulthood. Life span planning includes planning for the day when you will no longer be able to care for your family member. Seen in the light of an adult who is thriving – and not merely surviving – because of your good work is, indeed, a good thing. By planning together, you may provide them with what they most desire – a life lived to its fullest.

Picture your family member as an adult living in a community of people who understand and care for them, living with peers – disabled and non-disabled – of varying abilities and working a job that is fulfilling, challenging and rewarding. Planning can make this happen.

Planning can provide an environment that best nurtures the independence and dignity of your family member. Without such planning, you can never be sure whose choices will be achieved and whose voices will be hushed.

Think of PLAN as an acronym for Picking from Life's Assorted Necessities, or perhaps Planning, Learning, Accessing and Navigating. It's your choice how you view it, but keep in mind that to choose not to plan is a choice in itself, and one that will greatly affect the quality of the adulthood of your beloved relative or friend with disabilities.

Choosing to plan will be the first of many choices. Maybe you've heard that it is a difficult route. It doesn't have to be. With this guide, we plan to make it easier for you.



## HOW TO USE THIS GUIDE

This guide is intended to help you plan for the personal and financial future of your family member with a physical, mental or developmental disability. While it will cover trusts and estates, wills, government benefits and services, it will also touch on the emotional power of making decisions with someone you love.

Speaking of power, remember: Knowledge is power. You've heard it before but never, perhaps in such critical terms. You and your family member have the power to affect the quality of life this person will have. The knowledge to plan your family's future is in this guide.

This guide provides you and your family member with information to plan the way this individual will live out their life. This guide also takes into consideration the death or possible disability of those who do the planning. It's a very real part of everyone's life, and one for which you must plan.

Planning has a time line of its own. There is no set progression for any person whether disabled or not to achieve goals, but there is a natural progression in the way in which families need and use the knowledge available to them to help their children. Stated plainly, you don't need information all at once, but you need it all eventually.

***We suggest you use this guide in several different ways. First, read this guide once all the way through to familiarize yourself with the options available. Then, share with your family member who will be included in the plan. Finally, we recommend you keep it handy for ready reference.***

This guide is not intended to replace the role of a knowledgeable estates and trust attorney experienced in future care planning – for you will, in fact, need an attorney. This guide is designed to provide you with the knowledge you will need to work with an attorney. A similar guide has been written specifically for attorneys.

Throughout this guide are terms you will want to remember. They are defined in the Glossary at the end of this guide. You will find a list of where to get help in New York State at the end of this guide as well. In the Appendices are copies of forms you will need during financial planning.

## FREQUENTLY ASKED QUESTIONS

### Who should plan?

It is not only parents who should plan. Grandparents, guardians, aunts, uncles, nieces, nephews, cousins, sisters, brothers, and friends need to be involved in the planning process.

### What is the goal of planning?

- To give the person with disabilities an opportunity to receive some tangible assets (financial and personal property) during his/her lifetime to allow him or her a better quality of life.
- To assist that person in maintaining needs based benefits; i.e., Supplemental Security Income (SSI) or Medicaid.
- To insure that persons enjoy quality of life by receiving appropriate support and services.
- To give people with developmental disabilities control over where they live how long they live there, with whom they live and who assists them in their daily life.
- To give persons with disabilities choices.
- To give a family a feeling of comfort about their child's future.

### What does planning entail?

Long term planning includes making decisions about future needs in the areas of education, housing, employment, and support services, legal, financial and other personal matters.

### When should we plan?

- Immediately upon diagnosis of disability.
- When your daughter/son is between age 15 and 16, when, as required by *The Individuals with Disabilities Education Act (IDEA)*, she/he will receive "transitional planning" at school to prepare for adulthood.
- At the onset of a serious illness in the family.
- When your daughter/son turns 18 years of age.
- When your daughter/son is about to complete special education at age 21.
- When the family and/or daughter/son is awarded a malpractice/personal injury award following a lawsuit.
- When receiving a retroactive lump-sum payment from the Social Security Administration.
- Before you or your spouse die.
- Continually.

*This last item is important.* You will have to continually be thinking and planning as you and your family member mature and develop abilities that may offer new opportunities. Just as you plan for retirement and change those plans to meet

your changing wants and needs, so too should plans for your family members' future years be updated to meet their changing wants and needs.

When your family member is diagnosed as having a developmental disability, you should immediately develop a financial plan for their future supplemental needs. By taking such action, you will be enhancing your plan.

Consider this: There is another question that families ask all the time. It is also something of a declaration. It goes like this. "I pay my taxes." "I thought the government would take care of everything?" "Why should I have to plan at all?"

### **Why plan?**

According to national statistics persons relying solely on government benefits typically have very low income. You need to develop a financial plan to supplement government benefits. The personal and financial future and stability of your family member is partially within your control. There is a number of sound legal and financial features you can build into your family member's future care plans to ensure her/his well being. Even if you do not have substantial assets you can make choices about how your resources can supplement whatever government benefits are available.

***What is important is your desire to do the best for your family member. Be patient, be open-minded and never forget your dreams for them.***

### **Why we don't plan?**

Over the past several years, there has been considerable effort and training throughout the United States devoted to assisting parents in providing for the future of their family member with developmental disabilities. This is especially true in New York State.

Despite the information and training available, we find that there is still a great deal of reluctance on the part of parents to plan. Most parents never make a financial plan for their family member with developmental disabilities. The reasons stem from very basic human factors.

There are **three common factors** that keep families from planning. We must all manage a way through them.

1. *Fear of our own mortality.* Writing a will, deciding who will assist and support our family member and who may benefit from our estate confronts our basic human fear of dying.

Committing the plan to paper clearly confronts us with our own vulnerability – no one is comfortable with doing so. But, we must accept the fate of all of us. Consider how much more comfortable you might feel about your own end if you knew that your affairs could be settled in

accordance with your desires. If you die without a will - or intestate – you guarantee that someone else is going to be making these decisions about your money, your home, your valuables and, most importantly, your family member. That person is a Surrogate Court Judge. The judge might decide who will be the guardian/executor of your family member, if you don't suggest that in your future plan.

2. *Fear of being unfair to our family member with disabilities.* While you might like to insure that the child with disabilities inherits an equal or larger share of your assets, you might be afraid that this will deny him or her public benefits such as Supplemental Security Income (SSI) and Medicaid.

The real question in this case is whether equal distribution of assets will be fair to the person with a disability. Many parents become immobilized when they realize that dying without a will (*intestate*) or with a will (*testate*) with equal distribution can cause problems. In either case, being left income or property could result in loss of public benefits. These benefits are needed for payment for food, shelter, clothing, medical costs and support services.

***The best way that families have found to protect benefits for their family member with disabilities is through the creation of a Supplemental Needs Trust(SNT).***

3. *Anxiety over selecting/hiring an attorney.* We wonder if the attorney will be expensive and whether the attorney will understand the unique circumstances of the family member's disability, and what role it plays in your family's dynamics.

Why shouldn't you prepare your trust? Certainly some it may be done on your own. A petition for guardianship, for instance, can be pursued *pro se* – that is, without an attorney. However, for families with a family member with disabilities, writing a will and the construction of a trust instrument under or outside the will – should be done with a knowledgeable attorney experienced in future care planning.

Being an informed consumer will assist you in finding an attorney experienced in future care planning and can help contain legal costs. With the information in this guide regarding estate planning, you will be able to describe to an attorney the parameters of your future care plan. This approach will reduce the attorney's research time and therefore cut the cost. If you approach an attorney stating that you are not sure what you want, the time consumed in translating your needs into a plan could become costly. It is important to remember that legal fees can be negotiated, and that many attorneys will not charge for the initial consultation. You can "shop around" before making the final choice of an attorney.



## **How do we find an attorney?**

One of the best references for an attorney may come from either a family whose situation is similar to yours, or through the advocacy groups associated with your family member's disability. You may also call the New York State Bar Association's Lawyer Referral Service in Albany, or your local county bar association for possible attorney's referrals. Other options include the New York State Commission on Quality of Care, Protection and Advocacy for Persons with Developmental Disabilities Program (PADD), NYS Office of Mental Retardation and Developmental Disabilities or the New York State Association of Retarded Citizens (NYSARC).

To assist you in evaluating the experience level of your attorney, you may want to consider the following: Is the attorney...

- Familiar with government benefits and entitlement programs that your family member receives and the various requirements for such programs?
- Experienced in elder, disability and estate planning law?
- Experienced with Supplemental Needs Trusts that benefit individuals with disabilities?
- Able to furnish you with samples of guardianship or special needs trusts, and the percentage of business that his/her law firm devotes to special needs trusts?
- Experienced with guardianship and the laws/regulations involved with it?
- Experienced in disability and estate planning topics.
- Willing to set an established set fee for the items you need.

Many attorneys do not charge for the initial visit, so it could be to your advantage to "shop around" before making the final choice of an attorney.

## **Understanding the role of your attorney**

The role of an attorney is to advise you of the laws affecting you and your family and how to best plan for the future. This will include creating strategies for planning to further a public-private partnership in which your funds supplement public benefit programs. Your attorney will advise you about the choice of trustees, fiduciaries, executors, and guardians and any legal problems that may arise from implementing the plan.

Your attorney cannot have any financial interest in any insurance, financial planning or investment products unless such interest is disclosed to you. Because of this, the attorney can act as an impartial advisor regarding the necessity or advisability of investing in any product and in the selection of the best product for your situation. While an experienced estate planning attorney will be able to guide you through the myriad benefit programs, it is essential that you have knowledge of those programs.



## **MAKING A PLAN**

### **Getting Started**

The best approach seems to be to “sit right down and write yourself a letter.” Well, not to yourself but to “whom it may concern.” It’s called a letter of intent and in it you will describe your son or daughter and list all the relevant individuals in his/her life and where they can be found. It is best to be as descriptive as possible about the present as well as your vision for their future care. The letter is freeform and describes how you want people to help your family member. Forms in the back of this guide will help you in this process.

The following outline may be helpful:

- Residence – does my family member want to own a home, rent, share with others, live in a group home;
- Leisure
- Transportation
- Education
- Employment
- Medical care
- Behavior Management
- Social
- Religious
- Finances
- Vacations
- Guardian/advocate
- Advance directives
- Burial – what plans are/should be made
- Hobbies.

*For further information, refer to Appendix 11: Letter of Intent Worksheet.*



## **Building a Planning Team or Circle of Support**

You should include people who are dedicated to positive long-term goals for the persons with disabilities. This includes mother, father, grandparents, aunts, uncles, cousins, siblings, nieces and nephews, of your daughter/son with disabilities, and as many of the following individuals and entities as needed.

- A lawyer who is thoroughly familiar with trust and estate planning in general, government benefits, and the specialized needs of people with disabilities.
- A future care/advocacy organization.
- A financial planner or insurance agent who is familiar with financial planning.
- An accountant who is familiar with the family's financial matters;
- A Trustee.
- A guardian (if needed).
- A service coordinator (case manager).
- A service provider.
- Other (interested friends, neighbors, clergy etc).
- Back up trustees or guardians.

Many of us already have some of these people in our lives. Maybe a member of your family always prepares the taxes and is knowledgeable on implementing the plan.

## TAKING STOCK OF YOUR SITUATION

Planning involves taking stock of your assets and family's situation.

The nature of your family member's disability will dictate how you should develop your estate plan. Many individuals have disabilities that do not affect their ability to manage financial matters. If such is the case, providing for them an inheritance should take into account the following factors. Does your family member with disabilities receive benefits such as SSI, subsidized housing, personal attendant care, or Medicaid?

Even if the answer is no, you do not want to create an estate plan that will negate their benefit eligibility, if they should ever be in need of future assistance. Your plan should take into consideration the possibility that your family member's condition could worsen. Will your family member, for example, have the same capacity to earn money and manage an inheritance in twenty or thirty years, if their health should deteriorate?

It may be difficult for them to maintain employment or afford adequate healthcare. Government benefits might then become critical to your family member's financial security. Benefits include much more than money. For instance, your family member may be eligible for healthcare, vocational rehabilitation, supported employment, subsidized housing and personal attendant care.

Assets acquired through inheritance may affect eligibility for government benefits. In order to protect your family member's eligibility and adequately provide for their long term needs, you should establish a Supplemental Needs Trust (SNT).

If your family member with disabilities is not eligible for government benefits, you may be thinking of leaving them money outright. If you choose to do so, you should take into consideration their ability to earn money and handle their finances in the immediate and distant future. If you believe that this person's disability may reduce their financial earnings capacity, you may wish to leave a greater portion of your estate to this person. If you are concerned that this person will not be able to handle an inheritance, then you can utilize an SNT or a Guardianship to administer funds for his or her care.



## TAKING STOCK OF FINANCIAL ASSETS

Proper planning entails taking inventory of your financial assets. Fortunately, a variety of resources are within your reach:

- Government Benefits and Entitlements;
- Family/Friends Assistance;
- Inheritance;
- Investments;
- Insurance;
- Savings;
- Parents' Estate;
- Property;
- Military Benefits and
- Home, co-op or Condo.

Be sure to inventory all of these items that may be specific to your family. Estimate the size of your estate. Keep in mind that the will you write governs your affairs at the time of your death, so it must be flexible enough to meet changing situations. It is highly recommended that you update your will on a regular basis.

### INVOLVE YOUR FAMILY MEMBER

You should include your family member with disabilities in any discussion of their future whenever possible. We realize that the concept of estate planning can be frightening. It means picturing a time when you will not be there to advocate for your family.

Surprisingly, you may find that a discussion of many of these issues can actually be a great relief to your family member with a disability. They may be very worried about what will happen when you are no longer there to provide assistance. You know exactly what your family member can grasp and contribute to planning for their future.



## GOVERNMENT BENEFITS

In general, government benefits programs can be grouped into two categories:

- The first group is ***needs-based programs*** that are available to persons with disabilities who may qualify because of low income and limited savings. Examples are Supplemental Security Income (SSI), Food Stamps, Medicaid and rental subsidies.
- The second group of benefits is classified as ***social insurance programs*** that may be available to people with disabilities regardless of income or property based on an entitlement. Examples are Social Security Disability Insurance (SSDI) and Medicare.

### **Medicaid**

Medicaid is a health benefits needs-tested program funded and administered jointly by the federal, state and local governments. It is available primarily for needy families and pregnant women as well as for needy persons who are blind, have a disability or are age 65 or over.

Some services covered by Medicaid include:

- Necessary medical services provided by physicians;
- Hospital or skilled nursing-facility;
- Home health care services;
- Outpatient or clinical services;
- Independent laboratory and X-ray services;
- Service coordination/Case management;
- Clinical services;
- Personal care;
- Transportation to Medicaid covered services;
- Nursing care;
- Durable medical equipment.

If a person is eligible for Medicaid and Medicare, Medicaid can be used to supplement the coverage provided by Medicare.

If a person does not initially qualify for Medicaid because of her/his income or asset level, the person may qualify on a month by month basis by documenting medical expenses which when subtracted from personal income and assets would bring down the income to the eligibility level. This is known as the Spend-down Program or the Surplus Income Program in New York City. People with excess income can now also pay that amount directly to the local social services districts through a program called Pay-In.

## Medicaid Waivers

The federal government allows New York State to offer several Home and Community Based Services waivers to targeted populations. Federal Medicaid requirements that can be waived include state wideness, comparability and the treatment of income and/or resources. In addition to medical services that are available to all Medicaid recipients, waiver enrollees may also be provided with additional supports and services to enable them to live in the community, rather than an institution. Waiver programs typically provide community based support services such as respite and habilitation services.

Two waivers used by people with developmental disabilities in New York State are the Office of Mental Retardation and Developmental Disabilities (OMRDD) Home and Community Based Services (HCBS) Waiver, and the Care At Home (CAH) Waivers. Children enrolled in the OMRDD/HCBS Waiver can be treated as a "household of one" meaning that parental income and resources are not considered available to the child in the Medicaid eligibility determination. Children enrolled in the CAH waivers must first be determined **ineligible** for Medicaid when the income and resources of their legally responsible relative(s) are considered. In the second step of their enrollment, the child's Medicaid eligibility is determined as a "household of one".

The OMRDD HCBS Waiver is for adults and children with developmental disabilities who meet the Intermediate Care Facility (ICF)/MR level of care. Services include: Residential Habilitation, Day Habilitation, Pre-Vocational Services, Supported Employment, Adaptive Devices, Environmental Modifications, Respite, Plan of Care Support Services, Family Education and Training, Transitional Services, Consolidated Supports and Services. Availability of these services allows an individual greater independence and inclusion in the community.

Through the CAH Waivers, developmentally disabled children (as defined by the Social Security Administration) under the age of 18 who live at home and have a complex health care need may have access to Medicaid. In addition to medically necessary state plan services, enrollment in CAH gives the child access to three waiver services not provided through "regular" Medicaid: case management, respite and home adaptations. Availability of these services can make home care an option for children and their families. Medicaid enrollment applies only to the child.

**For more information call the Office of Mental Retardation and Developmental Disabilities at 518-474-5647.**

**Child Health Plus (CHP) and Family Health Plus (FHP)** - There are two other federal programs, in addition to Medicaid, that provide health insurance coverage to low income, uninsured children, families and single individuals.

Depending on your family's income, your child may be eligible to join either *Child Health Plus A* (formerly Children's Medicaid) or *Child Health Plus B*. Both Child Health Plus A and B are available through dozens of managed care providers throughout the state. Enrolling in Child Health Plus is easy. To be eligible, a child must meet the following criteria:

- Be under the age of 19.
- A New York State resident.
- Not eligible for Medicaid.
- Not have any other health insurance coverage.
- Available to all children regardless of immigration status who otherwise qualify.

*For more information on Child Health Plus, call the toll free number 1-800-698-4543 or visit the website at [www.health.state.ny.us/nysdoh/chplus/cplus-1.htm](http://www.health.state.ny.us/nysdoh/chplus/cplus-1.htm).*

Family Health Plus (FHP) provides health insurance to low income adults between the ages of 19 and 64 who have income that disqualifies them for Medicaid. FHP provides health care services through a managed care plan. The benefits package includes primary and preventive care, pharmacy, family planning and inpatient and specialty hospital care. Services not covered are non-emergency transportation, most medical supplies and non-prescription medications and long term care services for the chronically ill. There are no costs to participate in FHP.

To be eligible for Family Health Plus, an adult must meet the following criteria:

- Be age 19 through 64.
- A New York State resident.
- Meet citizenship/alien requirements.
- Not eligible for Medicaid because of income.
- Not have any other health insurance coverage.
- Have income level that falls below the maximum for the size of the family.

*For more information on Family Health Plus, call the toll free number 1-800-934-7587 or visit the website at [www.health.state.ny.us/nysdoh/fhplus/index.htm](http://www.health.state.ny.us/nysdoh/fhplus/index.htm).*

**Food Stamps** - The federal food stamp program is intended to relieve hunger and malnutrition among low-income households. A household may be defined as a single individual or several people who live together and prepare meals together for consumption at home. Applications for food stamps must be made to the local Department of Social Services district office or at a Social Security Administration (SSA) office when filing for other benefits.



To qualify for Food Stamps, there are maximum standards for income and assets which vary by the size and composition of the household. Any household where all members are receiving SSI or public assistance will be deemed eligible (that is, exempt from the income and resource standards) for food stamps. Generally, to apply, an applicant must be a resident of the local social services district (usually the county) in which she/he is applying. Once authorized, a person uses a card similar to a credit card to buy food.

*For more information on Food Stamps, call the toll free number 1-800-221-5689 or visit their website at <http://www.fns.usda.gov>.*

## **Social Security Administration**

The Social Security Administration (SSA) processes and administers benefit programs for individuals who have disabilities that create barriers to employment. *Supplemental Security Income (SSI)* and *Social Security Disability Insurance (SSDI)* are two such programs run by SSA.

- **Supplemental Security Income (SSI)** - These benefits are needs-based and may be available to individuals with disabilities who have very little income and resources. The funds are designed to supplement the income of people who are elderly, blind or disabled and lack sufficient resources to provide for their own needs.

The amount of the monthly benefit received from SSI depends on the person's income and living arrangements -- that is whether the person is living independently, with others, or is being supported by someone else, such as a parent, and any other income she/he may have. Receiving food stamps and government rent subsidies do not reduce benefits.

Disability benefits continue until the age of 65. As long as the individual meets the criteria for coverage, there is no length of time before she/he stops receiving benefits. Social Security requires periodic submission of medical evidence of need.

- **Social Security Disability Insurance (SSDI)** - provides benefits to disabled or blind individuals who have paid into the Social Security program through payroll taxes on their wages or to individuals who have been dependent on another person who has paid into the Social Security program. Typically a child who is disabled prior to age 22 collects Social Security benefits on a parent's work record when the parent retires, becomes disabled or dies.

Applications for Supplemental Security Income and Social Security Disability Insurance can be filed at a local Social Security office. If a person is unable to go to the local office, someone else may file the application. The application may also be filed over the telephone or over the internet. Social Security will usually

require a face-to-face interview with one of its representatives, but a home visit can be scheduled.

Everyone who receives Social Security disability benefits is required to notify SSA of any change in their living situation, resource level or income that may affect their monthly benefit within 10 days after the month of the change.

*For more information on filing for SSI or SSDI, call the toll free number 1-800-772-1213 or visit the Social Security website at [www.ssa.gov](http://www.ssa.gov)*

### **SSA's Definition of Disability**

The definition of disability under the Social Security Administration is different than other programs. Social Security pays only for total disability. No benefits are payable for partial disability or for short-term disability.

Disability under Social Security is based on an individual's inability to work. SSA considers an individual disabled under Social Security rules if the individual cannot do work that she or he did before and SSA decides that the person cannot adjust to other work because of the medical condition(s). The disability must also last or be expected to last for at least one year or to result in death.

This is a strict definition of disability. Social Security program rules assume that working families have access to other resources to provide support during periods of short-term disabilities, including workers' compensation, insurance, savings and investments.

**Substantial Gainful Activity (SGA)** - Substantial Gainful Activity (SGA) is the performance of significant and productive physical or mental work for pay or profit. For individuals receiving SSDI, SGA is used in determining initial and continuing disability entitlement. For SSI recipients, except for blind individuals, it is only used in determining initial disability entitlement. It does not apply to blind SSI recipients in determining initial eligibility.

The SGA level is average countable earnings over \$800 per month, as of January 2003, for non-blind SSDI and SSI recipients. For blind recipients, as of January 2003, the SGA earnings level is \$1300 per month. These amounts change annually. To calculate countable earnings, the Social Security Administration will deduct from gross earnings the cost of items a person needs in order to work and the value of support a person needs on the job due to impairment.

In general, if an individual earns more than what is called the Substantial Gainful Activity (SGA) level, it is difficult to establish eligibility for SSA benefits. However, each person's circumstances should be individually evaluated.

*For more information on Social Security call the toll free number 1-800-772-1213 or visit the website at [www.ssa.gov](http://www.ssa.gov).*

**PLANNING NOTE:** *People with disabilities are often kept from working if their family mistakenly believes that work will result in a loss of disability payments. Working without losing benefits until wages are enough to achieve financial self-sufficiency is a good example of the value of planning. The use of SSA Work Incentives is essential for good life planning.*

## **Work Incentives**

One of the Social Security Administration's (SSA) highest priorities is to help people with disabilities achieve independence by helping them take advantage of employment opportunities. Employment supports help a person to enter or re-enter the workforce by protecting eligibility for cash payments and/or health care.

### **Plan for Achieving Self Support (PASS)**

One of these programs is the Plan to Achieve Self Support (PASS) which allows a person to set aside income or resources for a specified time for a work goal. For example, saving to purchase a wheelchair accessible van, for instance, could be allowed under this plan without jeopardizing benefits. The income set aside under a PASS is not considered when figuring the SSI payment amount. Also, resources set aside under a PASS are not counted towards determining initial and continuing eligibility for SSI. A PASS must be approved by SSA.

### **Trial Work Periods**

Both Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) permit recipients to work without immediately risking their benefits. The SSDI program allows persons to attempt to work for nine months (not necessarily consecutively) without jeopardizing their benefits. After the trial work period of nine months, there is a three-year period during which eligibility for monthly benefits depends on the amount of wages earned. Medical benefits can continue throughout this period. The specific amount of benefits depends on the person's prior earnings and any type of worker's compensation benefits she/he may be receiving.

### **Special SSI Payments for People Who Work – Section 1619 (a)**

Individuals with disabilities (except those who are blind) can receive SSI cash payments even when earned income is at the Substantial Gainful Activity level, currently \$800 per month. To qualify, the person must have been eligible for an SSI payment for at least one month before beginning to work at the SGA level, still be disabled and meet all other eligibility rules, including the income and resources test.

## **Continued Medicaid Eligibility – Section 1619 (b)**

Medicaid coverage can continue even if a person's earnings along with other income become too high for an SSI cash payment. To qualify for Section 1619 (b), a person must have been eligible for an SSI cash payment for at least one month, still be disabled, still meet all other eligibility rules, including the resources test, need Medicaid in order to work and have gross earned income that is sufficient to replace SSI, Medicaid, and any publicly funded attendant care. A "threshold amount" is used to measure whether earnings are high enough to replace SSI and Medicaid benefits.

## **The Ticket to Work Program**

This new program, administered through the Social Security Administration, increases the choices for a person with disabilities in obtaining employment support services, vocational rehabilitation services and other services needed to get and keep a job. The program is being phased-in nationally over a three-year period. The first tickets were issued early in 2001 to select states, including New York. By 2004, the program will be available in all states.

SSDI and SSI disability beneficiaries receive a "ticket" they can use to obtain services from an approved provider of their choice called an Employment Network. The program is voluntary and the services will be provided at no cost to the individual.

*For more information on the Ticket to Work Program go to SSA's web-site at [www.ssa.gov/work/Ticket/ticket.html](http://www.ssa.gov/work/Ticket/ticket.html).*

## **Impairment-Related Work Expenses (IRWE)**

The costs of certain impairment-related items and services that a person needs to work can be deducted from gross earnings in figuring SGA, even if these items and services are also needed for non-work activities. These deductions can only be made if the cost of the item or service is paid by the person with the disability and the person has not been, and will not be, reimbursed for the expense.

The amount a person pays toward the cost of the items and services is deducted from the gross earnings. Only after these expenses are deducted is a determination made as to whether "countable earnings" represent SGA.

## **Special Rules for People Who Are Blind**

Persons with blindness may qualify for benefits even if they are working. Higher monthly earnings are allowed by Social Security for persons who are blind than for non-blind persons with disabilities before the employment is regarded as substantial gainful activity. Blind persons with disabilities also benefit from more deductions from the gross earnings when determining the income for SGA purposes, as well as in counting income for SSI eligibility.

For more information on work incentives or to obtain a copy of the current “*Red Book on Employment Support*,” go to SSA’s website at [www.ssa.gov/work](http://www.ssa.gov/work). For information or clarification on Social Security programs go to their website or call or visit your local SSA office.

## **Medicare**

Medicare is a federal health insurance program primarily for persons age 65 and over and for certain persons with disabilities. Unlike Medicaid, Medicare benefits do not vary from state to state and Medicare beneficiaries do not have to meet any income or resource standards. It is administered by the Centers for Medicare and Medicaid Services (CMS), which is part of the U.S. Department of Health and Human Services. The claims, however, are processed by private insurance companies under contract with CMS.

Medicare insurance benefits are provided for:

- Persons age 65 who are eligible to receive Social Security or Railroad Retirement benefits.
- Persons who have received Social Security or Railroad Retirement disability benefits for 24 months and have reached the age of 20; certain persons suffering from end-stage renal disease.
- Medicare-qualified government employees.

Many individuals with disabilities will qualify for Medicare as an additional benefit if they receive SSA disability benefits based on a parent’s work record. Medicare is divided into Part A and Part B.

*Medicare Part A*, also called hospital insurance, covers inpatient hospital care, post hospital care in skilled nursing facilities, certain home health care and hospice care for terminally ill patients. For insured persons, there is no monthly premium.

*Medicare Part B*, also called Supplementary Medical Insurance, covers physicians’ services, diagnostic tests, durable medical equipment (canes, walkers), ambulatory surgical services, rural health clinic services and ambulance services.

Persons receiving Part B must pay a monthly premium. When someone becomes eligible for Part A, they are offered the option of enrolling in Part B. While this involves paying a monthly premium, it is strongly suggested that Part B enrollment be accepted. If at a later date the person decides to enroll in Part B, the premium will be much higher. In many instances, low-income individuals with disabilities have their premiums paid for by the State.

Most people with disabilities who work will continue to receive at least 93 consecutive months of hospital and medical insurance under Medicare. The 93 months begin the month after the last month of the trial work period. The

individual must work and perform SGA, but not be medically improved. There is no Part A premium paid during the 93 months. After premium free Medicare Part A coverage ends due to work, it is possible for an individual to buy continued Medicare coverage as long as she/he remains medically disabled and is under 65 years old.

*For more information on Medicare, call the toll free number 1-800-633-4227 or visit the website at [www.medicare.gov](http://www.medicare.gov).*

### **Veterans Affairs (VA) Benefits**

The Department of Veterans Affairs (VA) pays two types of benefits, compensation and pensions, to veterans and their dependents. Surviving spouses and unmarried children under age 18 of deceased veterans may be eligible for a pension based on need if they meet the applicable income standards. Otherwise qualified children who become permanently incapable of self-support because of a mental or physical defect before reaching age 18 may receive a pension as long as the condition exists or until they marry. Effective October 1, 1997, children of Vietnam Veterans born with spina bifida became eligible for monetary benefit/monthly allowance from the Department of Veterans Affairs.

*For more information on VA benefits, call the toll free number 1-800-827-1000 or visit the website at [www.va.gov](http://www.va.gov).*

### **Railroad Retirement Benefits**

The Railroad Retirement Act established a compulsory pension system for railroad workers and their dependents upon the worker's retirement, disability or death. A person who thinks that he or she may be eligible for Railroad Retirement Benefits may file an application at one of its district offices serving New York State. To obtain the telephone number of the district office that serves your county, call (518) 431-4004.

*For more information visit the Railroad Retirement Benefits website at [www.rrb.gov](http://www.rrb.gov).*

### **Heating Assistance Program (HEAP)**

HEAP assists low income individuals and families with their heating and cooling costs.

The Low Income Home Energy Assistance Program (HEAP) is a federally funded energy assistance program. New York's grant is allocated among OTDA for a heating benefit program, the State Division of Housing and Community Renewal for weatherization activities and the State Office for the Aging, for outreach and referral activities. Applications are taken at all local departments of social services. *For information on where to apply, call 1-800-342-3009.*

## **Housing Choice Voucher (Section 8) Rental/Homeownership Subsidies**

The U.S. Department of Housing and Urban Development (HUD) funds public housing authorities, states, and other nonprofit entities to administer this rental or home ownership subsidy. One third of an individual's income must be applied toward housing expenses. The remaining housing costs can be covered by rental or homeownership vouchers up to the HUD established fair market value of the area. In selected areas, the voucher can be used for down payment for a home or an ongoing payment of a mortgage. Housing Choice vouchers are portable and can move with the person.

In some instances the rental assistance is tied to a building and therefore is not portable. This is called a project based voucher or certificate. You can access housing choice vouchers through your local housing authority, municipality, nonprofit housing agencies on the New York State Division of Housing and Community Renewal (DHCR). *You can reach DHCR @ 518-473-2083 or [www.dhcr.state.ny.us](http://www.dhcr.state.ny.us).*

## **Rural Housing Services Rental Assistance**

For persons living in rural areas rental subsidies are available through Rural Housing Services which is a unit of the U.S. Department of Agriculture. You can call 315-477-6400 or go to their website at [www.ruraldev/usda.gov](http://www.ruraldev/usda.gov).

## **New York State Division of Housing and Community Renewal (DHCR)**

This New York State housing agency administers a number of affordable housing programs including affordable apartments, and homeownership programs. You can call DHCR at 518-473-2517 or access their website at [www.dhcr.state.ny.us](http://www.dhcr.state.ny.us) for information on affordable housing in your area. Included on their website is a listing of affordable housing opportunities.

## **STAR**

The STAR Program allows home owners to reduce their school taxes depending upon their income levels. Please contact your municipality or town clerk for more information.

## **Telephone Lifeline**

Your local phone company offers a reduced monthly service rate for persons or families receiving government benefits listed above. Please contact your local phone company for further information.



## EDUCATION

When planning for the future of your family member, it is very important to inform the care giver as well as any trustee of the trust your intentions for their education. (Reference more on this under Trusts)

When we talk about education for people with disabilities, we are predominantly talking about special education services for students 3-21 years old that must be provided in the least restrictive environment. This is defined as instruction which is specially designed to meet your family member's unique needs, and can include classroom instruction, physical and vocational education, provided in schools, hospitals, institutions or other settings.

The right to an education for a person with disabilities is protected under a federal law called *The Individuals with Disabilities Act*, or *IDEA*; in the Appendix you will find a list of *IDEA*'s definition of disabilities. Planning for education needs and interests during adult years is also important. Adult education or computer classes, dance or art lessons and college courses are important additions to the quality of one's life. For more information go to the NYS Education Department's website [www.nysed.gov](http://www.nysed.gov), and specifically review the school-to-work transition area.





## EMPLOYMENT AND DAY SERVICES

***The purpose of employment and day services is to help individuals with developmental disabilities become participating members of their communities.***

Employment related services should be selected based on their ability to provide opportunities for community inclusion, participation, and contribution. When planning for the future of a person with a disability consideration should be given to consumer choice, focusing on what the person wants, including his/her dreams, interests and abilities. Employment and day services planning should be coordinated whenever possible, with planning for the individual's housing, transportation and other support needs. Based on the person's desires and support needs any combination of day services may be selected. For example, an individual receiving supported employment services to help him keep a job at a video store may also be receiving day habilitation services to access the fitness center and to continue his voluntary experience at his church and attend an art class.

Employment and day services are available to individuals with developmental disabilities throughout New York State. Listed below is a brief description of each employment and day service funded by OMRDD. For more information and/or assistance in accessing these services contact the Developmental Disabilities Services Office (DDSO) responsible for the county in which the person with a disability lives. You can locate your local DDSO at [www.omr.state.ny.us](http://www.omr.state.ny.us)

### **Supported Employment**

Supported employment is paid competitive work performed by individuals with severe disabilities who require support needs to obtain and sustain employment. It is performed in a normal work setting that provides opportunities for regular interactions with individuals who do not have disabilities and are not paid caregivers. The supports and services provided in supported employment may include: job development/job finding, situational assessment and reassessment, job coaching, skill training, improving work behaviors, mobility training, work-related socialization skills, and employer-co-worker training and support. To access this service you should contact your local Vocational and Educational Services for Individuals with Disabilities (VESID) district office, which can be located on the VESID website at [www.vesid.nysed.gov](http://www.vesid.nysed.gov)

### **Supported Self-Employment**

Supported self-employment promotes self-employment among people with developmental disabilities. Simply, supported self-employment means that the person with a disability owns his/her business and receives support and ongoing assistance in the day-to-day running of the business. Such supports may be provided to the individual for the life of the business. The supports are similar to those provided to people in supported employment. The business owner with a

developmental disability receives the supports and assistance necessary to initiate, develop and carry on the business activities. The specific types of assistance depend on the business owner's skills, and the types of natural supports he/she secures. OMRDD does not fund business start-up expenses or ongoing business expenses. Business start-up funds need to be accessed from other sources. The DDPC will have a guide entitled "*Supported Self Employment: A Guide To Assisting Individuals with Developmental Disabilities*" will be available on the DDPC website at [www.ddpc.state.ny.us](http://www.ddpc.state.ny.us)

### **Day Habilitation**

Day Habilitation services are aimed primarily at developing those activities and skills outside of a person's home that assist him/her in developing a full life in his/her community. The services help an individual become a contributing member of his/her community as well as develop satisfying and rewarding connections and relationships. These services can be provided almost anywhere, indoors or outdoors, in which an individual wishes to learn new skills.

### **Prevocational Services**

Prevocational services prepare an individual for paid employment. Prevocational services teach such concepts as following directions, attending to task, task completion, problem solving, and safety. Basic understanding of job performance requirements is also an important aspect of prevocational services. The purpose of the service is habilitation rather than teaching a specific job skill. This service may be provided in an integrated community setting or at a sheltered workshop/work center.

### **Day Treatment**

Day treatment is a planned combination of diagnostic, treatment, and habilitation services provided to persons with developmental disabilities in need of a broad range of clinically supported services. This service also focuses on providing community experience for people, but they must begin and end their day at the day treatment center.

### **Sheltered Workshop/Work Centers**

Sheltered workshops/work centers provide paid work to people with disabilities in a controlled and protective work environment. Participants are considered "client workers" rather than employees of the workshop. Workshops usually subcontract with businesses to provide meaningful work for people with disabilities. Typically workshop participants are paid by "piece rate" and earn below the minimum wage.

## **The Americans with Disabilities Act (ADA) and the right to work**

Both you and your family member are protected in your jobs despite the existence of their disability and how it affects your family. This protection is provided under the Americans with Disabilities Act (ADA).

### **For further information**

Title I of the ADA prohibits employers with 15 or more employees from discriminating against an employee or potential employee who is a “qualified individual with a disability” in all aspects of her or his work relationship, including hiring, promotions, training and termination.

The ADA’s protection applies also to those who have family members with disabilities and includes a non-disabled person who is the spouse or parent of a person with a disability. In this way, an employer may not refuse to hire an individual on the grounds that she or he has a family member with a disability, for example, and must make reasonable accommodations to the employee in light of the related person’s disability.

Some helpful ADA web links include:

[www.pueblo.gov/cic.text/misc/disability/disrits/html](http://www.pueblo.gov/cic.text/misc/disability/disrits/html)

[www.usdoj.gov](http://www.usdoj.gov)

[www.disabilitylawupdate.com](http://www.disabilitylawupdate.com)

[www.bazelon.org](http://www.bazelon.org).



## **HOUSING OPTIONS**

There are over 300,000 New Yorkers with developmental disabilities. The New York State Office of Mental Retardation and Developmental Disabilities (OMRDD) is responsible for housing and residential services for persons with developmental disabilities. OMRDD presently provides housing for over 35,000 persons in a combination of group homes, supportive apartments, family care and their own homes. OMRDD also provides housing services that assist persons with developmental disabilities to locate, lease or buy, and access residential arrangements which are alternatives to traditional congregate living situations. Such assistance and living situations include shared or matched home sharing, independent living, HUD rental subsidy programs, low income home ownership initiatives. Wherever they live, many people with developmental disabilities need some assistance in their daily lives and therefore, when planning for housing for someone with disabilities, it is necessary to include a support services plan. Developing long-term housing solutions for persons with developmental disabilities can be challenging, but many options exist today which allow a person variety, control and flexibility. The range of housing opportunities varies from institutions to home ownership. Let's explore some of the possibilities:

### **Home Ownership**

OMRDD can assist you with a number of different mortgage products, some designed specifically for individuals and families with developmental disabilities. Other options might include family assisted or donated ownership or placing the home in a trust fund. The person with the disability or his/her family could, for example, use family savings, investments, and property and first-time home ownership programs to purchase a home. Ownership will not affect one's benefits. The use of a Supplemental Needs Trust may be appropriate to help the person or the family financially. In-home services may be provided through a home health care agency, an agency that serves persons with disabilities, a roommate or other community and family supports.

### **Rent or Lease**

This housing option exists for everyone and involves the use of the newspaper, friends, realtors or driving around. There are market rents or subsidized apartments available. The subsidized units may have waiting lists, but in many areas, housing managers are looking to fill some apartments with persons with disabilities, meaning such a person could move to the top of the list. Rental subsidies from local housing agencies, service providers or municipalities may help pay for the cost of housing related expenses. These subsidies include Rural Housing Services, Individual Support Services and Housing Choice Vouchers.

## **Home Sharing**

In home sharing, there is a home seeker and a home provider. The person with the disability may be either, depending upon the situation. Home sharing is a roommate-matching situation, where two or more persons share their housing expenses. In some living situations, a roommate may provide services to the other in exchange for free or reduced rent. For instance, an elderly person with a room to spare may be in need of income and may welcome a person with disabilities as a tenant.

## **Family Care**

Housing and supports are provided to persons with disabilities in a family setting other than the biological family. The host family receives funds to provide clothing, food, shelter, and other living expenses and, in some situations, funds for personal care services.

## **Group Homes**

In a group living program, the state, a private or nonprofit agency owns or leases a home, certified by OMRDD. The homes may be intermediate care facilities (ICF), Community Residences (CRs), Individual Residential Alternatives (IRA), supervised or supported apartments. Within the home there are state-mandated regulations concerning most aspects of how the home is run, who and how many people can live there, and how the home is staffed. Group homes have provided many persons opportunities to move out of large institutions or leave their parents' home as they grow older.

## **Where to get more housing information**

OMRDD Developmental Disabilities Services Offices (DDSOs) have a housing coordinator. The phone numbers of the DDSOs are listed in the appendix: *Where to Get Help in New York State*. DDSO staff can assist you in accessing a variety of housing and service providers. Service providers that specialize in providing housing and services for persons with developmental disabilities run residential programs ranging from group homes, apartments, etc. These agencies are good sources for specialized housing for persons with disabilities. There are also housing programs run by nonprofit agencies, municipalities, housing authorities, bankers, realtors, builders, developers, and area aging offices.

## **Choosing Among the Housing Options**

The decisions of how to choose a living arrangement must be determined by you and your family member. Make sure to visit all options. The previous examples provide the general rule for what you can expect. At this point, you might want to make a list of what is important to you for your family member. To the greatest extent possible, your family member should be consulted about what goals, dreams and plans they have about future housing.

# ESTATE PLANNING

## Estate Planning for Persons with Disabilities and their Families

Most people are familiar with the term “*estate planning*,” which refers generally to the arrangement of a family’s legal affairs to ensure the smooth and proper distribution of assets at death. Estate planning is often a multidisciplinary endeavor, and the estate plan will differ depending on the needs of the family and nature of the property that a family owns. Regardless of the extent of a family’s property, however, almost all estate plans will involve a will, and many will also involve the use of a Trust. Both of these instruments will be described in some more detail below.

For persons with disabilities and their families, there is an additional concern. Estate plans for these families must ensure that distributions of property for family members with disabilities are properly managed if the family member with developmental disabilities lacks the ability to manage the property for him or herself. These estate plans must also ensure that property inherited by a family member with developmental disabilities does not disrupt eligibility for government benefits. The tool most commonly used for this purpose is the “*Supplemental*” or “*Special*” Needs Trust, also discussed below.

## WILLS

### What is a Will, and what does it do?

A Will is a legal document that provides you instructions on how you would like your property distributed upon your death, provided you haven’t already done so before your death. In other words, a Will directs the distribution of “*probate property*,” or property that becomes part of your “*probate estate*” at death. If, for example, at the time of your death you are the sole owner of a piece of property, or you are the sole owner of a bank account, those assets will become part of your “probate estate,” and your Will directs who inherits those assets from you, and in what amounts. A Will only takes effect upon the death of the person who created it. Until then, the creator of the Will can revoke, alter or replace it as long as she or he remains capable of doing so. The person who creates the Will is called a “testator” (if a man) or a “testatrix” (if a woman).

It is important to remember that not all property will be subject to disposition by your Will. If, for example, you have a life insurance policy that designates your sister as a beneficiary, but your Will leaves everything to your two children, the life insurance proceeds will be paid to your sister upon your death, not to your children, regardless of the instructions in your Will. The same thing happens with a joint bank account or a piece of real property that is “jointly” held. When one joint owner dies, the other joint owner becomes the owner of the bank account or real property in full, regardless of what the deceased joint owner’s Will says. We say that these assets (the life insurance policy, the joint bank account, the jointly owned piece of real property) are “non-probate” property, because they don’t

require a Will to determine who the new owner will be. Other common types of non-probate assets are retirement funds held in a 401(k) or IRA, an “in trust for” bank account, or savings bonds that are payable upon death to a specific person.

Knowing which of your assets non-probate property is and which assets are probate property is very important when developing an estate plan. Even the most carefully drafted Will is of no use if none of your assets become part of your probate estate and subject to disposition by your Will. Making a detailed inventory of what you own and how your property is titled will help ensure that your estate plan takes all of your assets into account.

### **“Probating” the Will**

When someone dies, his or her Will must be “probated” before the instructions contained in the Will can be carried out. “*Probate*” refers to the process whereby a Will is brought to a court (called the Surrogates Court in New York State) for review by a judge, who ensures that the Will is truly a document signed by you. This process is called probating a Will.

Once the judge confirms that the Will is genuine, the Court will appoint someone, usually a person named in the Will, to collect the deceased person’s assets, pay their bills, and then distribute the property in accordance with the terms of the Will. This process is called the “administration” of the estate, and the person designated in the Will to handle the administration is known as an “executor,” or an “executrix”. The executor/executrix need not be an attorney.

### **“What else does a Will do?”**

In addition to directing the distribution of property, a Will also provides the deceased parent with the opportunity to select who will serve as guardian of his or her minor children provided that a guardianship was not established prior to death. For the parent of a child with developmental disabilities that will continue into adulthood, it is generally recommended that the designation of guardian and “stand-by guardian” be made if needed, while the parent is still alive and before the disabled individual reaches the age of 18. (See the guardianship section for more detailed information on the need for and process to become guardian).

### **“What if I die without a Will?”**

When someone dies without a Will, we say that they have died “*intestate.*” In such a case, that person’s property will pass according to the laws of “intestacy,” which involve a predetermined hierarchy of immediate and more remote family members referred to as the deceased person’s “heirs-at-law.” For a man who dies without a Will and leaves a wife and children, the laws of intestacy will pass everything to the wife. If the man dies with a wife and two children, his wife will take one half of his probate estate, and his children will share the other half. For those who die without spouse or children, the laws of intestacy will divide the property among more remote relatives.

***The most important thing to remember is that once you die without a Will, you have lost the ability to control who inherits your property. This can be especially problematic when one of the people who will be inheriting your property is an individual incapable of managing his or her own money, and who relies on public benefits to pay for income, health care, housing, and other essential needs.***

**“Must I include my son or daughter with disabilities in my Will?”**

No state requires that any parent leave money to or for the benefit of a child, with a developmental disability. If you decide not to leave your disabled son or daughter any property in your Will, you are free to do so. This is called “disinheritance,” and your intention to disinherit your child should be clearly stated in your Will. This option is not recommended due to the risks listed below.

Some parents make a conscious choice to disinherit their disabled children, often in favor of other children who are not disabled. Usually those parents are concerned that an inheritance will adversely impact the disabled child’s eligibility for government benefits. And for outright gifts to a disabled individual receiving means tested government benefits, the parents are correct: a direct inheritance of more than a normal amount will generally terminate eligibility for benefits until such time as the inherited property is “spent down” to the very modest eligibility level for the particular government benefit program.

***“I don’t want to disinherit my child, but she needs to maintain her government benefits in order to stay safe and secure. Can I just give my disabled child’s share to my non-disabled child and expect my non-disabled child to use those funds for his sibling’s benefit?”***

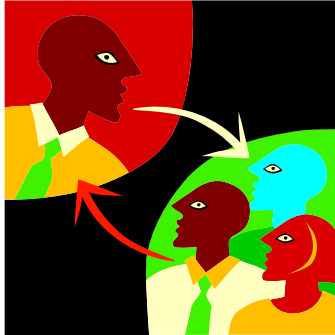
You certainly may, and in certain cases this arrangement may work just fine. It is important, however, that you consider the risks inherent in following such a plan. These “morally obligated” gifts are not enforceable, and even a sibling with the best intentions may be unable to ensure that those funds will be available for your disabled children when they are needed. For example, your non-disabled son may die, leaving all his property (including the “morally obligated” funds) to his surviving spouse. Or he may get divorced or sued himself, in which case all of his property will become subject to the payment of his own individual debts and obligations. And as difficult as it may be to accept, in some situations the non-disabled son or daughter may simply change his or her mind, and decide that the funds are better spent putting his own children through college or putting an addition on the house. Even the courts cannot help when this happens, because these morally obligated gifts are unenforceable. Therefore, this is not a recommended strategy.

***“If I cannot leave property directly to my disabled child, and I shouldn’t disinherit him altogether, then what options do I have?”***

The most common and efficient method of leaving property for the benefit of a disabled child is by creating a “Supplemental Needs Trust” designed specifically



for that purpose. These instruments, discussed in more detail in the following section, provide money management and financial supervision without jeopardizing government benefits, and ensure that your property will be available to enhance the quality of your disabled child's life.



## TRUSTS

### “What is a Trust?”

Trusts have been in existence for hundreds of years in our system of jurisprudence. They are, in essence, property management arrangements. Every trust has three essential parties. The first is the “creator” of the trust (often referred to as a “*Grantor*” or “*Settlor*”). In the most common future care plan, the parent is the creator of the trust. The second is the “*Trustee*,” the individual or entity (e.g., family member, bank, and investment firm or not-for-profit agency) that agrees to hold the property in trust. Usually the creator of the trust selects who will be the Trustee, and in certain future care planning situations, the Settlor (the parent) is also the trustee. The third is the “*Beneficiary*,” the person for whose benefit the trust is created. In a future care plan, the Beneficiary is the disabled son or daughter.

Trusts can be created during life by a written agreement between the Settlor and Trustee, in which case we call these instruments “*intervivos*” trusts. They can also be created at death under an article in a Will, in which case they are referred to as “testamentary” trusts. In this situation the executor (trix) would work with an attorney to establish the trust.

The property that is given by the Settlor to the Trustee is called the “*principal*” or “*corpus*” of the trust. Like any other property, the principal of the trust can be invested by the Trustee in the name of the trust, and earn interest or dividends, which are referred to as trust “income.” Depending on the terms of the trust, either principal, or income, or both, can be used for the benefit of the beneficiary.

## **“What is a Supplemental Needs Trust?”**

A Supplemental Needs Trust is an *“irrevocable”* trust, which means that once you put money into it, you cannot remove it for any other reason than to purchase items for services for the benefit of the Beneficiary with a disability. It can be created during life (an “intervivos” Supplemental Needs Trust) or at death (a “testamentary” Supplemental Needs Trust).

A Supplemental Needs Trust is also a “discretionary” trust, which means that the Trustee has great latitude in determining how the funds in the trust will be spent. If the Trustee does not make a distribution, the income and principal of the trust remain within the trust, to be used at some future point in time.

Supplemental Needs Trusts are created for the benefit of a person with a disability (The Beneficiary), and are generally designed to pay for things that “supplement,” and not supplant, goods and services received through government benefit programs. As long as the trust instrument clearly states that the trust is intended to be a “Supplemental Needs Trust,” the principal of the trust will not be considered “available” for the purpose of determining ongoing eligibility for most government benefit programs.

***There are two types of Supplemental Needs Trusts.*** The first type is known as a *“Third Party” Supplemental Needs Trust*. The term “third party” refers to the identity of the individual whose assets are being used to fund the trust. A Third Party Supplemental Needs Trust is funded with the assets of someone *other than* the individual with the disability. For example, a parent may leave a sum of money to a Supplemental Needs Trust created in the parent’s Will, and those funds will be held in trust for the disabled son or daughter (the “Beneficiary”), and used for the Beneficiary’s benefit until the funds are exhausted or until the Beneficiary dies. If any funds are left in the trust upon the death of the Beneficiary, those funds will be distributed to other individuals selected by the person who created the trust, often other family members. Unlike a “First Party” Supplemental Needs Trust (described below), there is no need to pay back the state for Medicaid benefits provided during the life of the disabled beneficiary.

The second type of trust is known as a *“First Party” Supplemental Needs Trust*. You may also hear this type of trust referred to as a “self-settled” or “payback” trust. The term “first party” also refers to the identity of the individual whose assets are used to fund the trust. A First Party Supplemental Needs Trust is funded with assets of the person with the disability, which may be available to that individual by way of a personal injury lawsuit, a direct inheritance, or employment income, bank payments or other sources of income. A First Party Supplemental Needs Trust is basically administered in the same fashion as a Third Party Supplemental Needs Trust during the life of the Beneficiary. However, upon the death of the Beneficiary, the State will have a priority right to be reimbursed for Medicaid benefits paid on the disabled person’s behalf during his or her life. This is often referred to as the “Medicaid lien” or “payback” provision. Only after the State has been repaid will any funds be available to distribute to other family members.

From a future care planning standpoint, parents and other family members considering a gift to a disabled individual would want to create a Third Party Supplemental Needs Trust, either during life (an *intervivos* trust) or in their Wills (a testamentary trust). This will ensure that any funds that are not used for the disabled family member will pass to other family members or other selected beneficiaries. If the parents fail to do so, and the disabled family member inherits those funds directly, then a First Party Supplemental Needs Trust will need to be created, and it will need to include the “payback” to the State upon the disabled individual’s death.

***Is there any benefit to creating the Supplemental Needs Trust right now (an “intervivos” Supplemental Needs Trust), rather than having it established through a Will at death?”***

The answer to that question depends on the needs of the parent or other individual who is considering funding the trust. In some cases, a Will with a testamentary Supplemental Needs Trust will be sufficient. But if there are other, ancillary reasons for the parent to be transferring funds out of his or her name (e.g., to accomplish a tax planning goal for the parent), then the *intervivos* trust may be advisable. Setting up an *intervivos* trust allows the beneficiary to utilize the resources of the trust throughout their lifetime. Other relatives, aunts, uncles, grandparents, may want to leave assets to the trust during the parent’s lifetime. Lifetime funding of a Supplemental Needs Trust should really be done in consultation with a financial and legal advisor. Transfers to *inter vivos* trusts may have tax consequences, especially for individuals with significant assets. For elderly parents or caregivers, transfers into an *intervivos* Supplemental Needs Trust may also have an adverse impact on the parents’ and caregivers’ ability to obtain Medicaid coverage for their own long term care costs, including coverage for nursing homes or certain types of home health care. Thus, while an *intervivos* Supplemental Needs Trust can be an extremely effective planning tool, it is also very important that the creation and funding of such a trust be part of a coordinated legal and financial plan.

***How do I select a Trustee?***

***Once you begin the future care planning process, the selection of the Trustee is perhaps the most important decision you will make in this area.***

Many Supplemental Needs Trusts fail to accomplish their intended goals because the Trustees were ill equipped for the task, or simply never received the training and information that is necessary in order to properly administer a Supplemental Needs Trust.

A Trustee’s obligations are many. They must ensure that trust funds are properly invested, and that all income received by and payments made out of the trust are properly accounted for. The Trustee should also have a basic understanding of

public benefits, and, perhaps most importantly, should know the disabled beneficiary and understands his/her disability.

Most banks have Trust Departments, and not-for-profit agencies (discussed in some more detail below) can serve as Trustees of Supplemental Needs Trusts. In addition, any competent individual over the age of eighteen (18) can serve as Trustee of a Supplemental Needs Trust, and can be just as effective as an institutional Trustee, provided that the individual Trustee has a proper foundation in trust management and public benefits. In fact, most Supplemental Needs Trusts name other family members as Trustees. In most cases, it is best to select a Trustee who is approximately the same age (or younger) than the disabled beneficiary. For example, the sibling of a mentally retarded woman would be more appropriate than an older aunt or uncle, because it is more likely that the aunt or uncle would predecease the disabled beneficiary, requiring a new Trustee to step in and be educated on Trust administration and management. In many cases, a parent may want to serve as Trustee (usually of an inter vivos trust) for the sole reason that the parent knows the disabled child better than anyone else. That is a perfectly understandable and appropriate choice of Trustee. In such a case, it is important to have an appropriate successor Trustee willing and able to serve if the parent becomes unable to do so.

***“Are there any other options available to create a Supplemental Needs Trust other than doing it myself?”***

Yes. You can use a Supplemental Needs Trust established by a not-for-profit organization. Unlike a trust prepared by an attorney as part of your individual estate plan, this type of trust is not privately drafted. This type of trust is known as a “pooled trust.” In a pooled trust arrangement, an individual contributes funds to an account managed by a not-for-profit organization, and the funds are combined and invested together with the funds of other contributors. Each contribution is recorded in a segregated account, and the not-for-profit agency makes distributions for the benefit of the person with the disability only from the funds in that person’s segregated account. As with private Supplemental Needs Trusts, income and principal held in a pooled trust will not be considered available in determining the ongoing eligibility of the disabled beneficiary for most government benefit programs.

Similar to the Supplemental Needs Trusts, there are **two basic forms** of pooled Supplemental Needs Trusts. *Third Party Pooled Supplemental Needs Trusts* are funded with the assets of other than the person with the disability, and *First Party Pooled Supplemental Needs Trusts* are funded with the assets of the person with the disability. Third Party Pooled Supplemental Needs Trusts often require a minimum amount to establish the account, and some organizations require that a percentage or other contribution can be made to the not-for-profit agency upon the death of the beneficiary. In New York, any funds remaining in a First Party Supplemental Needs Trust upon the death of the Beneficiary will remain in a First Party Supplemental Needs Trust, to be used for the benefit of other individuals served by the organization.

### ***What are the advantages and disadvantages of using a pooled Supplemental Needs Trust versus a private Supplemental Needs Trust?***

Using a not-for-profit organization as Trustee of a pooled Supplemental Needs Trust provides the beneficiary with a Trustee who has knowledge of disability issues, government benefits, and, in most cases, a proven track record. In addition, pooled trusts are less expensive to create (although pooled trusts do charge an ongoing administrative fee that is generally not charged when a family member serves as Trustee). Moreover, when there is no family member able and willing to serve as Trustee, the pooled trust may be the only option available to a disabled individual and his or her family unless the funds that will be held in the trust are significant enough to make hiring a corporate Trustee (i.e., a bank) worthwhile.

There are also some limitations relevant to pooled trusts that you should keep in mind. Many pooled trusts will limit how the trust funds are invested to a few conservative investments, usually interest bearing cash accounts.

For trusts that are established with more significant value, this limitation on how the funds will be invested can significantly detract from the long term growth of the trust plan, which in turn may shorten the duration that the trust will be available for the disabled beneficiary. If you are considering establishing a pooled trust with a significant amount of money and would like to have the money invested in a more aggressive fashion, you should discuss this with the pooled trust organization before you establish the account. In addition, most pooled trusts will not take title to real property, which may be a significant factor for a family hoping to leave family real estate in trust for the benefit of a disabled son or daughter.

Finally, if the pooled trust is established with a not-for-profit organization which is also serving as the direct provider of goods and services to the disabled beneficiary, there is a *potential* conflict of interest. Specifically, because the not-for-profit agency administering the pooled trust will retain all (or a specific percentage) of funds remaining in the trust upon the disabled beneficiary's death, some have argued that this dual role would serve as a "disincentive" to distribute funds during the life of the disabled beneficiary. However, most practitioners and advocates in this area who have worked with pooled Supplemental Needs Trusts believe this to be an academic argument, with little or no evidence of the conflict ever impacting proper and efficient trust management. Most not-for-profit agencies are dedicated to their mission and serve their disabled consumers in an honorable and honest fashion, and this is borne out in the manner in which they fulfill their role as Trustee.

### ***Once the Supplemental Needs Trust is established and funded, what types of things can the trust be used for?***

These trusts are designed to be used for goods and services that "supplement" the benefits that the beneficiary is receiving through government benefit

programs. All Supplemental Needs Trusts can be used to pay for recreational type items, such as movie tickets, computer equipment, health club membership, vacations, and other professional and support staff. These trusts can also be used to provide medical equipment or additional therapy not otherwise provided as part of the service package available to the beneficiary from his or her publicly funded health care provider. As a general rule, any expense that will enrich the life of the beneficiary is a proper expense. In addition, and depending on the type of government benefit program in which the beneficiary is participating, the trust can be used to pay for other, support type items, such as subsidizing rent payments so that the beneficiary can reside in a better neighborhood.

Whatever your intentions, it is important that the Trustee is aware of the specific needs of the beneficiary and the limitations on the use of trust funds particular to a given government benefit program. For example, a Trustee of a Supplemental Needs Trust whose beneficiary is participating in the Supplemental Security Income (SSI) program will be limited in his ability to make distributions from the trust to pay for food, clothing, and shelter items. Alternatively, if the beneficiary is Receiving only Medicaid-funded benefits, and is not receiving SSI, then the trust may be able to subsidize those support type items without adversely affecting Medicaid coverage. For distribution of this type, the Trustee should consult with an advisor who has a working knowledge of the particular benefit program in which the beneficiary is participating.

***Are there any adverse tax consequences in establishing a Supplemental Needs Trust?***

The answer to that question will depend on how the trust is funded, whose assets will be used to fund the trust, and how the trust is administered. Because all trusts are independent taxable entities, the tax treatment of assets held within the trust will depend on how the trust is drafted.

In general, trusts of modest amount will not have any significant tax impact, either for the creator of the trust, or for the beneficiary. For trusts of a more significant amount, it is important that the attorney who is preparing the trust instrument have a working familiarity with income, estate and gift tax issues affecting these trusts, or you otherwise consult with a tax professional to provide you with advice in this area, as you would any other significant financial transaction.

***Do I Need an attorney to establish a Supplemental Needs Trust?***

Wills and trusts can be created without the assistance of an attorney, but as this is a specialized area of the law and there are instruments that you hope will last for the lifetime of your disabled son or daughter, we do not recommend that you attempt to create the Supplemental Needs Trust (or the Will creating the Supplemental Needs Trust) on your own.

***Rather than preparing the trust on your own, we would recommend that you spend the time to locate an attorney who has developed an expertise in this area of practice and who has worked with families like yours in the past.***

You may also consider interviewing more than one attorney to be sure that the one you have chosen is “the right fit.” Consult with staff at the agency that is providing services to your disabled son or daughter to see if they can recommend an attorney. You may also want to discuss this matter with other families whom you know to have gone through this process to get their input and recommendations as well.

***Once I have created the trust (or the Will creating the trust), is my future care plan complete?***

No. The final step in developing a comprehensive future care plan is the preparation of a **“Life Care Plan.”** Unfortunately, this final step is often the most overlooked. At least in theory, people appreciate the need to address the legal and financial issues discussed above. But once the parents and caregivers are gone and the assets have been protected for the benefit of the individual with the disability, many questions still remain. “How should the funds that the family has worked so hard to protect be used to truly enhance the life of the person with the disability?” “To whom should I, as Trustee or Guardian, look to for advice and suggestion when the person with the disability cannot speak on his or her own behalf?”

A Life Care Plan helps provide answers to these and similar questions for the family members, friends and advocates who will provide assistance and oversight after the primary caregivers are gone. It begins with ensuring that as much personal, financial, and other pertinent information concerning the person with the disability is stored in a single place and accessible for future reference. Many advocates use workbooks designed specifically for this purpose. The workbooks will usually request background medical information, financial information, family history, community contacts, and recreational preferences of the person with the disability. The workbooks also often request that the caregivers provide similar information about their own finances and family supports. This information can prove to be especially crucial for those who must step in and assist when the caregiver is seriously injured or dies unexpectedly.

Second, most Life Care Plans will include a *“Letter of Intent,”* which is a personalized, specific description of your disabled son or daughter, and his or her likes, desires, and general limitations. It will also describe your and your child’s wishes and intentions for your son or daughter, and how you would like those intentions carried out. In most cases, a Letter of Intent is designed to “fill in the blanks.” For example, a Letter of Intent may describe an activity that you do each year on your child’s birthday. It may include family traditions or religious practices. Basically, it is designed to ensure that those who step into your shoes when you are gone are aware of the “quality of life” issues that make life enriching and enjoyable. The only rule of thumb is that you be as comprehensive

and detailed as possible, as the more information a Trustee has, the better able he or she will be to make decisions for your disabled child's benefit.

***PLANNING NOTE: If you were to get up and leave town today, who would step in to handle your affairs? Does this person know where all of your pertinent financial information is stored? Have you provided him or her with the legal authority to access your funds and act on your behalf? Who breaks the news to the person with the disability? Who will step in to do what you have been doing all these years? Who stays in contact with the service coordinator or social worker? Who double checks to be sure that medication is being taken as prescribed? Who will make those calls when no one has heard from your son or daughter in days, and who will they call? And if you have someone in mind, have you provided this person with the information he or she needs to carry out your wishes? Does this person know about your son or daughter's needs preferences and dislikes?***

A well written Life Care Plan will be of great value to those people who will step in and assist your disabled family member or friends when you are no longer able to do so. And as uncomfortable as it is for many parents and other caregivers to face the topic, completing this piece of the Future Care Planning process often provides satisfaction and relief. Certainly the legal and financial components are equally as critical, but in most circumstances, competent counsel will be able to preserve some of the family's funds for the person with the disability, even if no planning whatsoever has been completed prior to the disability or death of the caregiver. This "crisis intervention planning" is always more expensive, time consuming, and will be conducted before a court as a matter of public record, but it can be done.

Once the parents or primary caregivers are gone, however, the ability to prepare a comprehensive and detailed Life Care Plan becomes quite limited. There may be an Individualized Service Plan to use as a reference, a dedicated service coordinator who might have some additional personal information, or some other family member or friend who could assist in compiling pertinent information, but none of these fallback references will ever replace the Life Care Plan prepared by the parent of the person with the disability.

***When should you begin thinking about Supplemental Needs Trusts, Life Care Planning and Future Care Planning?***

**Now!** If you are a young family who has recently learned that your child has a lifelong disability, then you should begin considering future care planning immediately. However, it is never too late to start. Even if your disabled son or daughter is an adult and has been living with you for your entire life, ensuring that some attention is given to his or her future needs is just as important as it is for a young family. **The important thing is to get started.**



## GUARDIANSHIP

When a person is unable to manage all or part of their affairs, it might be necessary for someone else to lend assistance. This person would advocate in your family member's best interest. If the person who is designated to look after your family member after you are gone is appointed in an unofficial manner – that is, without the use of the courts – he or she is called an *advocate*. If the person is appointed by the courts – in most cases, after being suggested by you or your spouse – then the person is the *guardian*.

The rights of the people who need guardians to help them manage various aspects of their lives is an issue that continues to be in flux. In the case of guardianship, a delicate balance needs to be struck in determining the extent to which a person's basic civil rights are to be curtailed by the judicial appointment of another person to act in their stead. The balance is not so delicate that it cannot be achieved. It is delicate enough, however, that you need to understand the full weight of designating someone else to make decisions for and/or with your family member. Often a parent will have themselves appointed guardian and name a standby guardian at the same time. Upon the death of the parent/guardian, the standby guardian can immediately assume the role/duties of a guardian.

Guardianship should be viewed as an individual tool, but to be so, it must be understood. Guardianship can be an important support and service for people with developmental disabilities. It can provide both advocacy and access to services. It can make the difference between someone continuing to live in the community or having to move to a facility. In fact, it can provide a degree of stability to the plan you develop with your family.

***There are two types of guardianship in New York State; Article 17-A of the Surrogate's Court Procedure Act and Article 81 of the NYS Mental Hygiene Law. They represent two very different approaches to guardianship***

### **Surrogate's Court Procedure Act (SCPA) Article 17-A**

Under Article 17-A, the appointment of a guardian is made after a diagnosis of mental retardation or developmental disabilities is made by two physicians or one physician and one psychologist. The statute does not specifically direct tailoring the powers granted to the guardian to the individual needs of the person with disabilities. In most instances, the surrogate court will appoint a guardian *ad litem* for the person with disabilities to assess whether the best interests of the person would be served by the appointment of a guardian. Under 17-A, a nonprofit organization can be appointed guardian. Article 17-A can be done *pro se*, or without an attorney, and requires a filing fee of approximately \$15 - \$25, making it the least expensive of the two statutes. The petition for guardianship must be filed on standard forms created by the New York State Chief Administrator of the Courts. Some local courts have modified the standard

forms; therefore, the clerk of the guardianship department of the local surrogate's court should be contacted to obtain the local court forms, as well as, to find out if there are any special requirements or special practices of the court.

### **Guardianship of the person and/or property under Article 17-A**

The court may appoint a guardian of the person with disabilities, or of the property of that person, or of both person and property under 17-A. Often there is no property except the Social Security Disability payments that can be managed, if necessary, through the appointment of what is known as a *representative payee* by the Social Security Administration. If this is the case, a guardian of the property may not be needed.

Alternately, if only the authority to make medical decisions is being sought, a guardian of the person may be all that is needed. In a case where guardianship is sought only to receive and conserve funds, perhaps including the creation of a Special Needs Trust, a guardian of the property may be all that is needed.

### **Limited guardianship of the property under Article 17-A**

The court may appoint what is known as a *limited guardian* of the property. This type of guardian may manage only property that is not wages or earnings of the person with disabilities. In such cases, the person with disabilities must be at least 18 years of age and wholly or substantially self-supporting. The person subject to limited guardianship may enter into contracts of a value not to exceed one month's earnings or \$300, whichever is greater, or as other authorized by the courts.

The language of Article 17-A does not specifically provide for the limiting of the authority of the guardian of the person. However, a recent case (see Colette G., Nassau County Surrogate's Court, No. 263, March 15, 1994) seems to set some precedent for the court's ability to limit guardianship of the person under Article 17-A. SCPA Section 1755 authorizes modification such as limiting of the court order upon application to the court by the person subject to the guardianship or someone else on behalf of that person for protection of the individual's financial or personal interests. This section was added pursuant to Chapter 675 of the Laws of 1989 to enhance the rights of the individual.

### **Standby guardian**

Most guardianships begin with the parents being designated guardians after the person with disabilities reaches the age of 18. It is important, however, that parents appoint standby guardians at or near the same time. These are the people who will assume the legal authority to care for the family member with disabilities when the parents are no longer able to do so. The standby guardian is permitted to assume the guardianship duties immediately upon the death or disability of the parents, subject to the court confirmation within 60 days.

## **Health Care Decisions**

In becoming the guardian of the person, the individual takes on the decision-making ability for the person who is mentally retarded/developmentally disabled, especially as it relates to elective medical surgery. However, many physicians may accept the signature of the parent for surgery even if he/she is not the guardian; this is totally at the discretion of that physician. Issues of medical consent have become somewhat more complicated because of the problems associated with malpractice claims. Some health care facilities are now allowing only legal guardians to sign for medical consent. Furthermore, the law has been amended effective March 16, 2003, Chapter 500 of the Laws of 2002, to explicitly provide a guardian of a person with mental retardation with the authority to make health care decisions for such persons including decisions regarding life-sustaining treatment under certain circumstances. If the person who is mentally retarded/developmentally disabled lives in a facility licensed or operated by the Office of Mental Retardation/Developmental Disabilities (OMRDD), the Mental Hygiene Law and regulations will allow the parent to consent to many different matters on behalf of the person who is not capable of doing so even if they have not been appointed legal guardians.

### **Chapter 500 of the Laws of 2002**

Section 1750-b of the Surrogate's Court Procedure Act (SCPA) added by Chapter 500 of the Laws of 2002, provides that a guardian of a person with mental retardation has the authority to make any and all health care decisions on behalf of the person with mental retardation and that such person could make if such person had capacity unless the authority is limited by the Court. Such decisions may include decisions to withhold or withdraw life-sustaining treatment but not suicide, assisted suicide or euthanasia. Chapter 232 of the Laws of 2003 extended this authority to corporate guardians of persons with mental retardation appointed pursuant to 1750 of the SCPA. The authority to make life-sustaining treatment decisions was extended by Chapter 744 of the Laws of 2005 to guardians of persons with developmental disabilities if appointed pursuant to section 1750-a of the SCPA, and the ward has mental retardation or a similar impairment.

Chapter 500 added many safeguards to decision-making by guardians. The guardian shall base all advocacy and health care decision-making solely and exclusively on the best interests of the mentally retarded person and, when reasonably known or ascertainable with reasonable diligence, on the mentally retarded person's wishes, including moral and religious beliefs. Best interests is defined to include consideration of: the dignity and uniqueness of every person; the preservation, improvement or restoration of the mentally retarded person's health; the relief of the mentally retarded person's suffering by means of palliative care and pain management; the unique nature of artificially provided nutrition or hydration, and the effect it may have on the mentally retarded person; and the entire medical condition of the person. No health care decision shall be influenced in any way by: a presumption that persons with mental retardation are

not entitled to the full and equal rights, equal protection, respect, medical care and dignity afforded to persons without mental retardation or developmental disabilities; financial considerations of the guardian, as such considerations affect the guardian, a health care provider or any other party.

***The guardian shall have the right to receive all medical information and medical and clinical records necessary to make informed decisions regarding the health care of the person with mental retardation***

In regard to life-sustaining treatment decisions by a guardian of the person with mental retardation, the guardian shall have the affirmative obligation to advocate for the full and efficacious provision of health care, including life-sustaining treatment. In the event that a guardian makes a decision to withdraw or withhold life-sustaining treatment from a mentally retarded person: the attending physician and another physician or psychologist with special qualifications must confirm that the mentally retarded person lacks capacity to make health care decisions. Furthermore, the attending physician, in consultation with another physician, must determine to a reasonable degree of medical certainty that the mentally retarded person has one of the following medical conditions: a terminal condition, permanent unconsciousness; or a medical condition other than such person's mental retardation which requires life-sustaining treatment, is irreversible and which will continue indefinitely; and the life-sustaining treatment would impose an extraordinary burden on the person, in light of such person's medical condition, other than the person's mental retardation; and the expected outcome of the life-sustaining treatment, notwithstanding the person's mental retardation.

In the case of a decision to withdraw or withhold artificially provided nutrition or hydration, the doctors must confirm that there is no reasonable hope of maintaining life; or the artificially provided nutrition or hydration poses an extraordinary burden.

***For Further Assistance and Information***

*For further assistance with Article 17-A Guardianship, you can call the New York State Commission on the Quality of Care's Protection and Advocacy Program for guidance in using petition forms. Phone: 518-381-7102, e-mail [bill.combes@cqcaped.state.ny.us](mailto:bill.combes@cqcaped.state.ny.us) or NYSARC 518-439-8311. All 17A guardianship forms with instructions are available at [www.cqcaped.state.ny.us/guardfrm.htm](http://www.cqcaped.state.ny.us/guardfrm.htm)*

## **Article 81**

Article 81 is very different. Being a product of the 1990s, it reflects more recent thoughts on the abilities and rights of persons with disabilities. Its provisions include the necessity of a diagnosis of the actual abilities of the person with disabilities including how they function on a daily basis. In this way, it is more individualized than its predecessor. Provisions are made for a court evaluator

and counsel for the person with disabilities in some cases under Article 81. Payment for such counsel has recently been upheld by an appeals court for people who are indigent.

In an Article 81 appointment, the authority of the guardian is clearly stated. Finally, Article 81 includes provisions for annual reports (under 17-A, reporting is only required for guardians of the property, not the person with developmental disabilities) and for the training of evaluators, court examiners and guardians. The filing fee is approximately \$270, however, attorney fees for the petitioner and the individual will also be required in most instances.

### **Types of Guardianship under Article 81**

Article 81 provides for “tailored” or “limited” guardianship over the person with disabilities, his or her property, or both. These limitations will be based specifically on the functional abilities of the person with disabilities and will be tailored to those limitations. Thus, under Article 81, each guardianship appointment is unique.

Obviously, there are significant differences between the two statutes. Article 17-A is usually the quicker and less expensive route to the appointment of a guardian, and provides a court order giving the guardian power over the financial and/or, personal care of the person with disabilities. On the other hand, Article 81 provides for individualization of the court order and requires training for the guardian and court evaluators. In addition, Article 81 provides extensive accounting requirements. Under certain conditions, Social Security or conserved SSI funds can be used to pay for the cost of pursuing guardianship.

### **Corporate Guardianship**

As we mentioned before, there are alternatives to designating a family or friend as guardian. If no relative, friend or neighbor is available to serve as guardian, the guardianship statute contains a provision which permits a not-for-profit corporation having corporate authority in its charter to act as guardian of the person only. For a listing of corporate guardianship programs, refer to Appendix V: ***Where to Get Help in New York State.***



## BURIAL PLANNING

No one likes to think about funeral and burials. For many people with disabilities, it may be essential for someone else to make these provisions. Although the following contains only information as it pertains to Medicaid and SSI, we recommend that everyone makes arrangements to include them in the Life Care Plan.

In determining the resources of an individual, the value of any burial space that is intended for the use of an individual, their spouse, or any immediate family member is excluded from being counted as an available resource for Medicaid eligibility. Immediate family includes the individual's minor (younger than 18), and adult son/daughter, step-son/daughter, and adopted son/daughter, brothers, sisters, parents, adoptive parents, and spouses of those persons. Dependency and living in the same household are not factors to be considered. Burial space items should include, but aren't limited to: burial plots, caskets, headstones, engraving, and opening and closing the grave.

Burial funds are those set aside to meet the expenses connected with the individual's burial, cremation or other funeral expenses. The law provides that funds set aside in a special account for the burial expenses of an individual are excluded from Medicaid eligibility purposes up to a limit of \$1,500 for each person. The limit will be reduced by the following:

- The face value of any life insurance policies, except term insurance, with a total face value of \$1,500 or less;
- Any amount held in an irrevocable trust or other pre-need burial arrangement for non-burial space items.

If the individual is filing for SSI or Medicaid, funds that exceed the resource limit can be put into a burial fund in order to make the applicant eligible for benefits. This cannot exceed \$1,500 with the exception of interest earned and retained in the burial fund. Excess funds may be used to prepay funeral expenses, purchase cemetery plots, markers, etc.

*New York State ARC (NYSARC) conducts training on end-of-life care. Contact them at 518-473-8311 or at [www.nysarc.org](http://www.nysarc.org).*



## INTERSTATE MOVES

Perhaps you and your spouse are planning to move to another state when you both retire. To do so, you must make plans for the continued services for your family member, whether they are going to move with you or remain in New York State.

In terms of relocation, it is important to know that every state has different qualifications, paperwork and waiting periods for setting up services and residences for people with developmental disabilities. Residential services will require a longer waiting period, with some states reporting as much as a three to four year waiting list. Many states require that a relative or guardian live in the State with the person with disabilities.

Planning begins with informing your Developmental Disabilities Service Office (DDSO), or other agency that assists your family member. The agency will be able to tell you about the requirements, paperwork and waiting time for each state. There is a considerable amount of paperwork involved and it is critical, therefore, that you plan for the move well in advance.

Moves within New York State take less time but also require paperwork and planning. Please consult your local service agency and inform them of your plans to move as soon as you have made such arrangements.



## GLOSSARY OF TERMS

**Activities of Daily Living** - Activities such as, but not limited to, mobility, eating, toileting, dressing, grooming, housekeeping, cooking, shopping, money management, banking, driving or using public transportation and other activities related to personal needs and to property management.

**Available Resources** - Usually, this refers to money and assets, but it can include resources such as, but not limited to, visiting nurses, homemakers, home health aides, adult day care and multi-purpose senior citizen centers, powers of attorney, trusts, representative payees and residential care facilities.

**Beneficiary** - The person for whose benefit a trust or insurance policy has been created.

**Bequest** - A gift made through a will.

**Discretionary Powers** - Powers that provide a trustee many options in managing Pa trust's assets.

**Disinherit** - To exclude from inheritance.

**Estate** - All property, both real and personal, that a person owns at the time of their death.

**Executor/Executrix** - The person responsible for collecting, maintaining, and distributing the assets of an estate, in accordance with the terms of the will.

**Functional Level** - The ability to provide for his/her personal needs and/or property management.

**Functional Limitations** - Behavior or conditions of a person that impair the ability to provide for personal needs and/or property management.

**Grantor, Settlor, Creator** - The person who establishes the trust.

**Guardian** – A person who, is eighteen years of age or older, a corporation, or a public agency, including a local department of social services, appointed by the Supreme Court, the Surrogate's Court, or the county court to act on behalf of an incapacitated person in providing for personal needs and/or for property management.

**Inter vivos Trust** – Established by the creator during his/her lifetime.

**Jointly Owned Property** – When two or more people jointly own property. (See Right of Survivorship).



***Least Restrictive Form of Intervention*** – The provision of services to meet the individual’s needs in a manner which least interferes with the individual’s normal day to day activities.

***Letter of Intent*** – conveys- “This is what I know about my son/daughter with disabilities and what I want as a parent for his/her care after I am gone.” It is a document that comprehensively describes, in a very personalized manner, updated information about likes, dislikes, needs and desires of the beneficiary in as much detail as possible. The letter of intent may include similar information as the life care plan, but is presented in a letter format.

***Life Care Plan*** – Is a much more comprehensive way of stating the information given in the letter of intent. It is a document that helps to provide instruction, convey the parent’s values, and state the intention that the wishes and needs of the son/daughter with disabilities are to be respected where appropriate. The life care plan is useful for attorneys, service providers or others who will be working with the son/daughter with disabilities.

***Luxuries Trust*** – A trust that supplements rather than replaces government aid. This is another name for a supplemental needs trust and is sometimes also referred to as an Escher or special needs trust.

***Mandatory Provisions*** – Statements contained in a trust that require the trustee to act in certain ways.

***Morally Obligated Gift*** – A gift or bequest given to someone with a request that the gift be used only for the benefit of a third party. It is not legally binding.

***Personal Needs*** – Needs such as, but not limited to, food, clothing, shelter, health care and safety.

***Personal Property*** – Everything other than real property, including cars, jewelry, and clothing.

***Pooled Trust*** – The pooling of resources for investment purposes established and managed by not-for-profit associations, which maintain separate accounts for each individual.

***Probate Court*** – The court that determines the validity of a will and then ensures that the will’s instructions are carried out.

***Property Management*** – Taking action to obtain, administer, protect and dispose of real and personal property, intangible property, business property, benefits, and income to deal with financial affairs related to property.

***Real Property*** – Real estate, land, home.

***Remainderment or Remainderperson*** – The person(s) or organization that receives the remaining assets of a trust at the trust’s termination.

**Right of Survivorship** – When ownership of jointly owned property dies, the remaining owner becomes the sole owner of the property. (See jointly owned property).

**Self-Settled Trust** – A living trust in which the beneficiary is the settler. Also known as a 1<sup>st</sup> party OBRA '93 or Medicaid payback trust.

**Settlor** – A person who establishes a trust-grantors, creator.

**Spendthrift Clause** – A provision in a trust ensuring that the beneficiary does not pledge or encumber the assets of the trust.

**Supplemental Needs Trust** – A trust which provides funds in addition to governmental benefits to a person with developmental disabilities. The assets of a Supplemental Needs Trust are not considered as “available assets” for the purpose of determining whether an individual is eligible for governmental benefits.

**Survivor** – The remaining owner of jointly owned property after the death of the owner(s).

**Testamentary Trust** – A trust established under a will to take effect after the death of the testator or testatrix (person).

**Third Party Trust** - A living trust or testamentary trust in which the beneficiary under the trust is someone other than the grantor or settler. Also known as an Escher trust.

**Trust** – A legal relationship created by one person, called the “settler,” in which another individual, the “trustee,” owns and manages property for the benefit of a third person, the “beneficiary.”

**Trustee** – A person who owns and manages a trust for a beneficiary.

**Trust Instrument** – The document that creates a trust.

**Will** – A legal document providing instructions for how an estate will be distributed upon death.

# APPENDIX I

## A PLANNING QUESTIONNAIRE

Most of these questions can be answered without the advice of an attorney. Do as many as you can and bring the results with you to your first attorney visit.

### A. ***What is the life impact of the disability?***

1. Can you describe the functional limitations of the disability?
2. Can your family member with a disability take care of himself?
3. Can the family member handle their own financial affairs?
4. Can the family member earn their own living, or at least part of it?
5. Can the family member live on their own or will they have to live in a group home or with other friends or relatives?
6. Does the family member have multiple disabilities?
7. Will the family member have extraordinary expenses? What kind and in what amounts?

### B. ***What are the finances of the person?***

1. What will be the overall financial needs of the family member?
2. Will the family member qualify for any federal or state benefits? Which ones?
3. Does the family member have assets, inheritances, pensions, benefits or other sources of income that will be used not qualify him from receiving SSI, Medicaid or other federal or state benefits based on need?

### C. ***What are your assets, needs and ability to provide for your family member?***

1. What are your financial needs?
2. Are there other family members who must or should be provided for?
3. What are the needs of others?
4. What assets do you have available and what are they worth? Are they liquid?
5. If your assets are not sufficient to use a bank as a trustee, is there a capable family member or a friend who will act as a trustee? Is there an experienced attorney or other professional willing to act as a trustee for a reasonable fee? Is there a standardized trust that you can adopt?

### D. ***What are the emotional issues and concerns of the family?***

1. How will other family members feel if the person with disabilities receives income from a trust for their needs?

2. How will the person with disabilities feel if they are cut out of the will and left to rely on federal and state benefit programs for their entire livelihood?
3. How will the person with disabilities feel about having siblings or other close relatives or friends controlling their assets and/or taking care of them?

**E. *Have you resolved all planning issues?***

1. Who will look after the person with disabilities after your death? It should be someone familiar with the person with disabilities and how to deal with those disabilities. Can you rely upon a social worker or other professional in the field?
2. Are there other family members or friends who are willing to help? On what basis? Do they have the time and necessary expertise? Can they be trained to handle the problems?
3. If no family member or friend can or will help, you may need outside help. Who can help you? What will you have to pay for such help?
4. Who can you get to be the trustee of a trust for the benefit of the person with disabilities? It may have to be someone other than whoever is assisting the person with disabilities, since different abilities may be needed.
5. Guardianship – If guardianship is needed who will be the guardian and succession guardian?
6. Trustees –Who will be the trustee and succession trustee? A family member, a bank, a law firm, an investment firm or a pooled trust? What will their fee, if any, will be?



## APPENDIX II

### Letter of Intent - Planning Work Sheet

For each applicable area below, consider your family member's future. But also try to think in terms of making these decisions for yourself. What would you want? List 3-4 options to guide future caregivers in decision making and interaction with your family member. Draw upon what you know about your family member, through observation and through discussion with your family member and share what you've learned. We've included some worksheets that can help you to record specific information. Please feel free to make copies of these pages.

- Residence:** If something should happen to you tomorrow, where do you want your family member to live?
- Education:** You have a lifelong perspective of your family member's capabilities. Share it!
- Work:** What has your family member enjoyed? Consider their goals, aspirations, limitations, etc.
- Health:** What has and has not worked with your family member? What should future caregivers know?
- Behavior:** What consistent approach has worked best in your absence during difficult transition periods in your family member's life?
- Social:** What activities make life meaningful for your family member?
- Religious:** Is there a specific church or synagogue or person your family member prefers for fellowship?
- Finance:** What financial resources are available for the plan?
- Mobility:** What arrangements are necessary to transport your family member to the above mentioned activities?
- Advocate:** Who will look after, fight for and be friends to your family member?
- Guardian:** List 3-4 options of persons  
Trustee(s): Who do you want to manage your family member's supplementary funds? List 3-4 persons your child's age that can act as a successor guardian.

Also list:

Likes  
Dislikes  
What works: living situations, foods, recreation  
What doesn't work  
Social/recreational activities  
Diet preferences  
Clothing preferences

# FAMILY LIFE PLANNING WORKSHEET

(adapted from Disabled and Alone Life Services for the Handicapped, Inc.)

## I. A brief introduction to us and our child:

Date Completed: \_\_\_\_\_

### Parents:

Father - \_\_\_\_\_

Address \_\_\_\_\_

Home Telephone \_\_\_\_\_

Business Telephone \_\_\_\_\_

Date of Birth \_\_\_\_\_

Social Security # \_\_\_\_\_

Mother (include maiden name) \_\_\_\_\_

Address \_\_\_\_\_

Home Telephone \_\_\_\_\_

Business Telephone \_\_\_\_\_

Date of Birth \_\_\_\_\_

Social Security No. \_\_\_\_\_

### Family Member with a Disability

Name \_\_\_\_\_

Living Arrangements \_\_\_\_\_ with parents, \_\_\_\_\_ with other family members,  
\_\_\_\_\_ independent, \_\_\_\_\_ institution/hospital, \_\_\_\_\_ supervised residence.

Address \_\_\_\_\_

Home Telephone: \_\_\_\_\_ Business Telephone \_\_\_\_\_

Date of Birth: \_\_\_\_\_ Social Security No. \_\_\_\_\_

Is your child married? \_\_\_ Yes \_\_\_ No

Does your child have children? \_\_\_ Yes \_\_\_ No

### Siblings

Name \_\_\_\_\_ Home Telephone \_\_\_\_\_

Address: \_\_\_\_\_ Business Telephone \_\_\_\_\_

Name \_\_\_\_\_ Home Telephone \_\_\_\_\_

Address \_\_\_\_\_ Business Telephone \_\_\_\_\_

Name \_\_\_\_\_ Home Telephone \_\_\_\_\_

Address \_\_\_\_\_ Business Telephone \_\_\_\_\_

**// Family's Wish for Future Care**

Date Completed \_\_\_\_\_

In the first column, if possible, have your family member rank the following items in importance with 1 being the most important. Then in the second column you rank the items in importance for your child *after you are gone*.

- \_\_\_\_\_ A good place to live \_\_\_\_\_
- \_\_\_\_\_ A reliable and caring person or organization to oversee and advocate (as needed) \_\_\_\_\_
- \_\_\_\_\_ Adequate private financial resources \_\_\_\_\_
- \_\_\_\_\_ Good medical and dental care \_\_\_\_\_
- \_\_\_\_\_ Friends to do social activities with \_\_\_\_\_
- \_\_\_\_\_ Live with friends \_\_\_\_\_
- \_\_\_\_\_ Meaningful daytime activities \_\_\_\_\_
- \_\_\_\_\_ A healthy diet \_\_\_\_\_
- \_\_\_\_\_ Regular religious services \_\_\_\_\_
- \_\_\_\_\_ Job/Employment \_\_\_\_\_
- \_\_\_\_\_ Appropriate transportation \_\_\_\_\_
- \_\_\_\_\_ Visits and contacts with relatives \_\_\_\_\_
- \_\_\_\_\_ Reliable care by home attendants \_\_\_\_\_
- \_\_\_\_\_ Spending money \_\_\_\_\_
- \_\_\_\_\_ Holiday and birthday celebrations \_\_\_\_\_
- \_\_\_\_\_ Entertainment (movies, hobbies, etc) \_\_\_\_\_
- \_\_\_\_\_ Vacations \_\_\_\_\_
- \_\_\_\_\_ Recreation \_\_\_\_\_
- \_\_\_\_\_ Other: \_\_\_\_\_

### III. Everything you need to know about our family member

**Knowledge:** For each area below write down as much of the “special knowledge” you have about your family member. Be as detailed and descriptive as possible. Record all information that you think would be helpful to a perfect stranger who may be providing care. To get started you might describe your family member’s typical day. For example: What toothpaste do they use? Does he/she use hot water, cold water or warm water to brush their teeth? What are his/her favorite foods, or foods they dislike? What hobbies does he/she enjoy? What is their favorite color? These examples may seem nonessential, but it is these every day little things that are important for all of us.

Likes:

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Dislikes:

---

---

What works:

---

---

What doesn’t work:

---

---

Housing Preferences:

---

---

Social/recreation activities:

---

---

Diet preferences:

---

---

Clothing preferences:

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**Faith/Religion:** \_\_\_\_\_ **Place of Worship:** \_\_\_\_\_

Religious practices/events \_\_\_\_\_

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**Important People:** List the names and address/phone numbers of any important people in your son/daughter's life not yet listed (e.g., friends, coworkers) and their relationship to your child.

Note: Family members will be listed later in this chapter.

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**Special Equipment and Supplies:** List any medical, adaptive, personal equipment your family member uses (e.g., wheelchair, special plate and utensils for meals, treadmill, or exercise bike, radio for focusing on tasks, TV or stereo)

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**MEDICAL HISTORY** COMPLETED \_\_\_\_\_

Current Physician: \_\_\_\_\_ Phone: \_\_\_\_\_

Address: \_\_\_\_\_

Specialists: (eye, podiatrist, neurologist, psychologist, hospital, dentist, etc)

Name \_\_\_\_\_ Phone: \_\_\_\_\_

Address: \_\_\_\_\_

Area of specialization: \_\_\_\_\_

Name: \_\_\_\_\_ Phone: \_\_\_\_\_

Address: \_\_\_\_\_ Phone: \_\_\_\_\_

Area of specialization: \_\_\_\_\_

Name: \_\_\_\_\_ Phone: \_\_\_\_\_

Address: \_\_\_\_\_ Phone: \_\_\_\_\_

Area of specialization: \_\_\_\_\_

Name: \_\_\_\_\_ Phone: \_\_\_\_\_

Address: \_\_\_\_\_ Phone: \_\_\_\_\_

Area of specialization: \_\_\_\_\_

Name: \_\_\_\_\_ Phone: \_\_\_\_\_

Address: \_\_\_\_\_ Phone: \_\_\_\_\_

Area of specialization: \_\_\_\_\_

Name: \_\_\_\_\_ Phone: \_\_\_\_\_

Address: \_\_\_\_\_ Phone: \_\_\_\_\_

History of Surgeries or Hospitalizations:

Date: \_\_\_\_\_

Incident: \_\_\_\_\_

Outcome: \_\_\_\_\_

Date: \_\_\_\_\_

Incident: \_\_\_\_\_

Outcome: \_\_\_\_\_

Date: \_\_\_\_\_

Incident: \_\_\_\_\_

Outcome: \_\_\_\_\_

Childhood Diseases: \_\_\_\_\_

\_\_\_\_\_

Medications:

Current prescriptions and dosage: \_\_\_\_\_

\_\_\_\_\_

Medication Allergies \_\_\_\_\_

\_\_\_\_\_

Allergies: (bee stings, red food dye, milk, animals, etc.)

\_\_\_\_\_

Special circumstances: (include here anything you feel is important but not covered)

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Family medical history: (list any family illnesses, diabetes, heart problems, kidney disease, cancer, etc. Make sure to include the relationship of the person to your son/daughter – Mother, Father, Sister, Uncle, etc.)

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**Finances**

Date Completed \_\_\_\_\_

a. How do we currently support our family member?

The first step in financial planning for your child’s future is to calculate how much money or time you spend on your child each month. This is personal money that you as a parent spent to either do the work yourself or pay to have someone else do the work. In some cases the work you do is a cost of time to you. It is important to make a note of that. Examples are given for some areas.

Check Appropriate Column:	\$ Amt	Hours per Month	Services you Provide
Benefit/entitlement monitoring <i>(Paperwork for SSI/Medicaid)</i>	_____	_____	_____
Representative payee	_____	_____	_____
Case management service <i>(Scheduling doctors appts)</i>	_____	_____	_____
Emergency Intervention <i>(Picking your child up from School or work because of An emergency)</i>	_____	_____	_____
Fees for service <i>(Extra therapy sessions, Respite care)</i>	_____	_____	_____
Health care supplements/ Insurance	_____	_____	_____
Rent/Housing <i>(if your child doesn't live with you do you pay part of Rent or utilities for him/her)</i>	_____	_____	_____

Housekeeping Laundry, cleaning, Food preparation	_____	_____	_____
Medication monitoring	_____	_____	_____
Socialization <i>Driving your child to social Events, arranging social Events.</i>	_____	_____	_____
Shopping <i>Clothes, food</i>	_____	_____	_____
Transportation <i>Driving child to/from School/work, day Activities</i>	_____	_____	_____
Other (explain)	_____	_____	_____
Total monetary or time	_____	_____	_____

List services that others provide without charge  
(E.g. volunteers, other relatives, friends)

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

b. Family Member's Government Programs – (include ID #s, monthly amounts, contacts)

SS/SSI/SSDI	_____
Medicaid	_____
Welfare	_____
Food Stamps	_____
HEAP	_____
Rent Subsidies	_____
Other (specify)	_____

OMRDD Services: Mark all that apply:

1.  Service Coordination
2.  In-home residential habilitation  
Services
3.  Respite
4.  Transportation
5.  Live in Companion
6.  Family Support Services
7.  Individual Support Services
8.  Residential Services
9.  Other (please list) \_\_\_\_\_
9.  E-mods
10.  Assistive technology

For those boxes checked above, fill in the blanks below with the name/s and address/s of agency/s providing services for your child. Also list what service they provide and give the name of a contact person at the agency.

1. Name: \_\_\_\_\_  
Address \_\_\_\_\_  
\_\_\_\_\_  
Service/s: \_\_\_\_\_  
Contact Person: \_\_\_\_\_  
Phone #: \_\_\_\_\_
2. Name: \_\_\_\_\_  
Address \_\_\_\_\_  
\_\_\_\_\_  
Service/s: \_\_\_\_\_  
Contact Person: \_\_\_\_\_  
Phone #: \_\_\_\_\_
3. Name: \_\_\_\_\_  
Address \_\_\_\_\_  
\_\_\_\_\_  
Service/s: \_\_\_\_\_  
Contact Person: \_\_\_\_\_  
Phone # \_\_\_\_\_
4. Name: \_\_\_\_\_  
Address \_\_\_\_\_  
\_\_\_\_\_  
Service/s: \_\_\_\_\_  
Contact Person: \_\_\_\_\_  
Phone # \_\_\_\_\_

c. Family Member's Income and Expenses  
 Date Completed \_\_\_\_\_

Use the following table to list all income and received each month by/for the person with a disability.

**MONTHLY INCOME**

SOURCE	AMOUNT
Employment (net amount after taxes)	
Social Security (SSI, SSDI, SSA)	
Government or private pensions	
Other government benefits (i.e. Veterans)	
Annuities	
Interest from savings, etc.	
Dividends from stocks, bonds, etc.	
Payments from life insurance policies	
Payment from a trust fund	
Other income: (list)	
Total Monthly Income	



Use the following table to record all expenses incurred each month by/for the person with a disability.

### MONTHLY EXPENSES

Expense	Monthly Total	Amount Family Provides
Housing rent, maintenance, taxes, mortgage, etc)		
Utilities		
Transportation		
Food		
Medical/Dental Care		
Clothing		
Personal Items		
Vacations		
Social/Recreational Activities		
Insurance (health, life, auto, etc)		
Personal Care Assistance		
Education		
Special Equipment		
Other Expenses: (list)		

Total Monthly Expenses		
------------------------	--	--

<b>PLANNING NOTE: INCOME MINUS EXPENSES DETERMINES NEED</b>
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IV. Our documents, accounts, assets/debt's Date Completed \_\_\_\_\_

**DESCRIPTION/LOCATION OF WILLS, TRUSTS AND SIMILAR DOCUMENTS**

DOCUMENT	LOCATION

SPECIAL INSTRUCTIONS:

**DESCRIPTION/LOCATION OF BIRTH, ADOPTION, MARRIAGE, MILITARY DISCHARGE, NATURALIZATION AND SIMILAR CERTIFICATES**

DOCUMENT	LOCATION

SPECIAL INSTRUCTIONS;



DESCRIPTION/LOCATION OF CREDIT CARD ACCOUNTS
--


SPECIAL INSTRUCTIONS:
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REAL ESTATE INFORMATION

RESIDENTIAL AND RECREATIONAL PROPERTIES
---

ADDRESS	PROPERTY #1	PROPERTY #2
Date Purchased		
Purchase Price		
Legal Owner		
Estimated Current Value		
Mortgage Amount Remaining		
Contact Person/Telephone		
Mortgage Insurance Carrier		
Contact Person/Telephone		

INVESTMENT AND COMMERCIAL PROPERTIES
--------------------------------------

ADDRESS	PROPERTY #1	PROPERTY #2
Date Purchased		
Purchase Price		
Legal Owner		
Estimated Current Value		
Mortgage Amount Remaining		
Contact Person/Telephone		
Mortgage Insurance Carrier		
Contact Person/Telephone		

SAVINGS INFORMATION

BANK ACCOUNTS – FATHER
------------------------

	ACCOUNT #1	ACCOUNT #2	ACCOUNT #3
Bank			
Address			
Account number			
Type of account: savings, checking			
Estimated Value			

**BANK ACCOUNTS – MOTHER**

	ACCOUNT #1	ACCOUNT #2	ACCOUNT #3
Bank			
Address			
Account number			
Type of account: savings, checking			
Estimated Value			

**OTHER ASSET INFORMATION**  
(Mother And Father)

Automobiles/other vehicles	Asset #1	Asset #2
Manufacturer		
Model		
Year		
Estimated Value		

Trust Funds	<u>Asset #1</u>	<u>Asset #2</u>
Value		
Paintings, Art, Collectibles, Jewelry, Furniture, Appliances (optional, you may want to make a separate list elsewhere and just estimate value here.)		
Total Estimated Value		

<u>OTHER</u>	ASSET #1	ASSET #2
Estimated Value		

**SUMMARY OF ASSETS AND REAL ESTATE**

ITEM	TOTAL VALUE
Residential/Recreation Properties	
Investment/Commercial Properties	
Company Pension Plan	
Retirement Savings Plan	
Insurance Policies	
Investments	
Bank Accounts	
Automobiles/Other Vehicles	
Trusts	
Paintings/Art/Collectibles/Jewelry etc.	
Other	
Total Value of All Assets	

**SUMMARY OF LIABILITIES**

ITEM	INSURED (YES/NO)	AMOUNT OWED	DEBT LIFE (If applicable)
Mortgages			
Car Loans			
Credit Cards			
Other Debts			
Total Liabilities			

**NET WORTH**

Total Value of all Assets	
Total of all Liabilities	
Net Worth (Assets minus Liabilities)	

Other Family Members, Advisors, Key People in Our Child's Life  
(List Names, addresses, phone numbers for each person)

Siblings \_\_\_\_\_  
\_\_\_\_\_

Attorney \_\_\_\_\_

Executor of Will \_\_\_\_\_

Trustee \_\_\_\_\_

Guardian \_\_\_\_\_

Clergy person \_\_\_\_\_

Family Friends \_\_\_\_\_

Other \_\_\_\_\_



SAMPLE

LAST WILL AND TESTAMENT

TESTAMENTARY  
SUPPLEMENTAL NEEDS TRUST  
SUGGESTED LANGUAGE

2006

*This publication is distributed with the understanding that the Developmental Disabilities Planning Council (DDPC) is not rendering legal, accounting or other professional advice or opinions on specific facts or matters, and, accordingly, assumes no liability whatsoever in connection with its use.*

*Families are strongly encouraged to consult with an attorney who has the knowledge and expertise in the estate planning process as it pertains to the special needs of persons with disabilities.*

## Trust Clause (For Wills)

### Suggested Language for Last Will and Testament

(Article #): I give and bequeath (the sum of \$ \_\_\_\_\_ or \_\_\_\_\_%) of my estate to my Trustee hereinafter named as a Supplemental Needs Trust for the benefit of (name of Beneficiary). My Trustee shall hold, manage and reinvest the same bequest and shall have the sole and absolute discretion to expend or not expend principal and/or income for the benefit of said beneficiary, subject to the following purposes, terms and conditions.

A. My Trustee shall hold, manage, invest and reinvest these funds and collect the rents, interest, dividends and other incomes therefrom. My Trustee in consultation with the lifetime guardian of said beneficiary shall pay the income and/or principal from this trust fund after proper charges and expenses to the guardian of the person or property of said beneficiary, or directly to a service or property provider for the benefit of said beneficiary, as requested by (her/his) guardian. My Trustee is authorized to pay from the income and corpus of this trust any sums that may be needed or useful in enhancing the lifestyle of said beneficiary, or for any costs or expenses it deems of extraordinary or compelling necessity. Any distribution from this Trust shall be at the sole discretion of the Trustee and not subject to our review.

B. Payments by my Trustee for the benefit of the person or property of said beneficiary's shall be made subject to the following uses and conditions.

1A) It is the testator's intent to create a supplemental needs trust which conforms to the provisions of section 7-1.12 of the New York Estates, Powers and Trusts Law. The testator intends that the trust assets be used to supplement, not supplant, impair or diminish any benefits or assistance of any federal, state, county, city or other government entity for which the beneficiary may otherwise be eligible or which the beneficiary may be receiving. Consistent with that intent it is the testator's desire that before expending any amounts from the net income and/or principal of this trust, the Trustee consider the availability of all benefits from government or private assistance programs for which the beneficiary may be eligible and that, where appropriate, and to the extent possible, the Trustee endeavor to maximize the collection of such benefits and to facilitate the distribution of such benefits for the benefit of the beneficiary.

1B) None of the income or principal of this trust shall be applied in such a manner as to supplant, impair or diminish benefits or assistance of any federal, state, county, city or the governmental entity for which the beneficiary may otherwise be eligible or which the beneficiary may be receiving.

2A) Neither income nor the principal in the hands of my Trustee, before the interest and/or principal is actually paid or delivered to the guardian of or for the benefit of said beneficiary, shall be subject to voluntary or involuntary anticipation, encumbrance, alienation or assignment, either in whole or in part, nor shall such interest be subject to any judicial creditors or claimant of said beneficiary.

2B) The beneficiary does not have the power to assign, encumber, direct, distribute or authorize distributions from this trust.

3) Certain needs of said beneficiary may be provided for by my Trustee from the income and/or principal, including additional food, clothing or health services not provided, stereos, tape recorders, VCRs, television sets or other electronic items, vacations, trips, birthday and holiday gifts, or similar tangible items, if they are not otherwise provided by governmental financial assistance and benefits or by the provider of services.

4A) Notwithstanding the provisions herein, the Trustee may make distributions to meet said beneficiary's need for food, clothing, shelter or health care even if such distributions may result in an impairment or diminution of said beneficiary, receipt or eligibility for government benefits for assistance but only if the Trustee determines that (i) said beneficiary's needs will be better met if such distribution is made, and (ii) it is said beneficiary's best interests to suffer the consequent effect, if any, on said beneficiary's eligibility for or receipt of government benefits or assistance.

4B) However, if the mere existence of the Trustee's authority to make distributions pursuant to this subparagraph shall result in the beneficiary's loss of government benefits or assistance, regardless of whether such authority is actually exercised, this subparagraph shall be null and void and the Trustee's authority to make such distributions shall cease and shall be limited as provided in paragraphs two and three above, without exception.

5) In making any distribution to or for the benefit of said beneficiary, the Trustee should consider what benefits said beneficiary may be entitled to from any governmental agency, including but not limited to Social Security Administration benefits, Veteran Administration benefits, Medicaid, including medical assistance and day-treatment program assistance and Supplemental Security Income benefits. I request that my Trustee assist said beneficiary, in collecting, expending and accounting separately for all such governmental assistance benefits but not commingle them with the trust fund.

6) This Trust shall terminate upon the death of said beneficiary. Upon the termination of this trust, my Trustee is directed to pay such portion of the burial costs and expenses including the cost of a burial lot and a

marker of said beneficiary, not covered by insurance or otherwise from (her/his) property other than the income and principal of this trust and to pay over and distribute the remaining principal and any accrued and accumulated income as follows: (Insert provisions for distribution of the remaining assets in the trust.)

Sample language to dispose of remaining assets in the trust.

(a) If not otherwise provided for, a sum to cover burial expenses including plot and grave marker.

(B) The balance of the principal and remaining income of the trust shall be paid in equal shares to my other children then surviving and to the issue of my deceased children, per stirpes and not per capita.





## APPENDIX IV

### SAMPLE THIRD PARTY (OR ESCHER) TRUST

(NOTE: This document is a sample only and should not be used to establish a trust, this is for reference only)

#### THIRD PARTY SUPPLEMENTAL NEEDS TRUST

This TRUST AGREEMENT, made this \_\_\_\_\_ day of \_\_\_\_\_, by and between \_\_\_\_\_, both having a Post Office address of \_\_\_\_\_ as \_\_\_\_\_ as "Trustees."

WHEREAS, it is the SETTLOR's intent, because of the severe and chronic or persistent disability of her son, \_\_\_\_\_ hereinafter referred to as the "BENEFICIARY," that this Trust shall be construed as a Supplemental Needs Trust which conforms to the provisions of Section 7-1.12 of the New York Estates, Powers and Trusts law. The SETTLOR intends that the Trust assets be used to supplement and not supplant, impair or diminish, any benefits or assistance of any federal, state, county, city, or other governmental entity for which the BENEFICIARY may otherwise be eligible or which the BENEFICIARY may be receiving. Consistent with this intent, it is the SETTLOR's desire that, before expending any amounts from the net income and/or principal of this Trust, the Trustees consider the availability of all benefits from government or private assistance programs for which the BENEFICIARY may be eligible and that, where appropriate and to the extent possible, the TRUSTEES endeavor to maximize the collection of such benefits and to facilitate the distribution of such benefits to the BENEFICIARY.

NOW THEREFORE, in accordance with the intent of the SETTLOR as expressed above, and in consideration of the mutual covenants herein contained, the TRUSTEES hereby agree to hold IN TRUST those assets described in the attached "SCHEDULE A", or hereafter acquired as permitted by this instrument, for the uses and purposes set forth herein.

1. NAME AND BENEFICIARY:

This Trust shall be known as the \_\_\_\_\_ THIRD PARTY SUPPLEMENTAL NEEDS TRUST.

2. IRREVOCABILITY:

The SETTLOR hereby irrevocably assigns, transfers and sets over to the TRUSTEES all of her right, title and interest in and to the assets described in the attached "SCHEDULE A."

3. DISTRIBUTION OF PRINCIPAL AND INCOME:

A. Principal:

The TRUSTEES may, in their sole and absolute discretion, invade the principal of this Trust if such invasion is necessary or desirable in order to supply the BENEFICIARY with services and items of need not otherwise provided through government entitlements.

B. Income:

The income herefrom shall be paid or distributed to or for the benefit of the BENEFICIARY in such amounts and at such times as the TRUSTEES may determine in their sole discretion. The income shall be distributed only for "Special Needs" of the BENEFICIARY that are not provided by government entitlements and as defined by this Trust. Any distribution by the TRUSTEES shall be made with a recognition of the "Special Needs" of the BENEFICIARY who, because of the nature of his disability, will be dependent on government entitlements for his life.

C. Investment of Principal in Appropriate Housing:

The TRUSTEES shall have the power to acquire and maintain proper housing for the BENEFICIARY. The TRUSTEES are encouraged to invest in property in whatsoever form as will maintain the BENEFICIARY in a home-like environment. Home-like environment shall not include nursing homes or institutions or any facility that would be financed by government entitlements.

D. Additions to Income and Principal:

With the TRUSTEES' consent, any person may, at any time, and from time to time, by Court Order, assignment, gift, transfer, Deed or Will, provide additions to the income or principal of this Trust. Any property so added shall be held, administered and distributed under the terms hereof.

E. Insurance:

The TRUSTEES shall have the discretion to purchase whatever insurance is necessary to make the BENEFICIARY financially secure, including private health insurance. Private health insurance may be purchased if it will result in providing for payment to those medical professionals or

medical providers who would otherwise not accept government entitlements.

F. Other Needs and Luxuries:

The TRUSTEES shall have the discretion to use the Trust funds to insure that the BENEFICIARY will enjoy the therapeutic benefits of education, vocational training, hobbies, vacations, modes of transportation, entertainment, and any other need and/or luxury that the BENEFICIARY may require to enjoy life. This discretion shall include the use of funds for needed medical care not paid for by private health insurance or government entitlements. This provision shall also include the purchase of any computer or similar equipment that would enhance the quality of life of the BENEFICIARY.

G. Employment of Professionals and Other Care Givers:

The TRUSTEES shall have the discretion to use principal and income from the Trust to hire professionals to assist the BENEFICIARY. It is contemplated that the classes of professionals who may be needed to assist the BENEFICIARY will or may be social workers, custodians, medical professionals, legal counsel, accounting professionals, investment counsel, feeders, therapists, and any other personnel who would not otherwise accept or be paid for by government entitlements.

H. Distribution of Trust Income:

The Trustees shall attempt to spend at least the minimal income of the Trust on the beneficiary each year.

I. No Elimination of Benefits:

None of the principal or income of this Trust shall be applied in such a manner as to eliminate, supplant, impair or diminish benefits or assistance of any federal, state, county, city or other governmental entity for which the BENEFICIARY may otherwise be eligible or which the BENEFICIARY may be receiving. Notwithstanding anything to the contrary contained herein, however, the TRUSTEES may make distributions to meet the BENEFICIARY's need for food, clothing, shelter or health care, even if such distributions may result in an impairment or diminution of the BENEFICIARY's receipt or eligibility for government benefits or assistance, but only if the TRUSTEES determine that (1) The Beneficiary's needs will be better met if such distribution

is made, and (2) it is in the BENEFICIARY's best interest to suffer the consequent effect, if any, on the BENEFICIARY's eligibility for or receipt of government benefits or assistance, provided, however, that if the mere existence of the TRUSTEES' authority to make distributions pursuant to this paragraph shall result in the BENEFICIARY's loss of government benefits or assistance, regardless of whether such authority is actually exercised, this paragraph shall be null and void and the TRUSTEES' authority to make such distributions shall cease and be limited as otherwise provided herein.

4. TERMINATION OF TRUST:

A. Termination Upon Death of Beneficiary:

This Trust shall terminate on the death of the BENEFICIARY. At such time, the TRUSTEES may pay such amounts as may be necessary for the funeral expenses or any estate, gift, trust or income taxes or other final expenses or debts that are or may be due upon or by reason of the BENEFICIARY's death.

B. Distribution of Remainder:

Upon the termination of the Trust, all principal and accumulated income remaining after the payments described in Paragraph 4(A). Above shall be paid over absolutely to \_\_\_\_\_ daughter of the SETTLOR, or to her issue in equal shares by representation if she has predeceased the BENEFICIARY.

5. SUCCESSOR TRUSTEE:

If either Co-Trustee should die or be otherwise unable to serve, then the Successor Co-Trustee shall be \_\_\_\_\_.

6. POWERS OF TRUSTEES:

In addition to any powers that may be conferred upon the TRUSTEES under the law of the State of New York in effect during the life of this Trust, the SETTLOR hereby confers upon the TRUSTEES all of those discretionary powers mentioned in Article 11 of the Estate Powers & Trusts Law, or similar statutes governing the discretion of TRUSTEES, so as to confer upon the TRUSTEES the broadest possible powers available for the management of the Trust assets.

7. COMPENSATION OF TRUSTEES:

No TRUSTEE shall be entitled to any compensation for his or her services herein.

8. RESIGNATION OF TRUSTEE:

Any TRUSTEE may resign by delivering notice of each resignation to the other TRUSTEE.

9. ANNUAL ACCOUNTING:

The TRUSTEES shall not be required to file an Annual Accounting to the BENEFICIARY. Trustees shall all file annual reports to Social Security Administration, Department of Social Services and pay income taxes to the IRS.

10. BOND:

No TRUSTEE shall be required to execute or file any bond with regard to the performance of his or her duties hereunder.

11. SPENDTHRIFT CLAUSE:

No interest in this Trust shall be subject to the claim of any creditor, nor to legal process and may not be voluntarily encumbered. The BENEFICIARY herein shall not have the power to assign, encumber, direct, distribute or authorize distributions from this Trust.

12. GOVERNING LAW:

All questions relating to the validity and construction of this Trust, the determination of the share of the BENEFICIARY, the dates, powers, authority and discretion of the TRUSTEES, and all other matters arising in connection herewith, shall be governed by the laws of the State of New York. In WITNESS WHEREOF, the SETTLOR and the TRUSTEES have executed this Agreement the day and year first above written.



## FIRST PARTY SUPPLEMENTAL NEEDS TRUST

This Trust Agreement, made this 29<sup>th</sup> day of March, 2002 between Also as "The Parent," residing at \_\_\_\_\_ Street, New York, hereinafter referred to as "Grantor," and Aldo hereinafter referred to as "Trustee."

WITNESSETH:

WHEREAS, the Grantor desires to create an irrevocable supplemental needs pay back trust for \_\_\_\_\_ and \_\_\_\_\_

WHEREAS, \_\_\_\_\_ is the child of the Grantor and is mentally disabled; and

NOW, THEREFORE, in consideration of the premises contained herein, the parties agree as follows:

1. Creation of a Trust. The Grantor herein transfers to the Trustee and the Trustee hereby acknowledges receipt of the property set forth in Schedule A, which property the Trustee hereby agrees to hold IN TRUST and administer the same, together with any other money and property that may be added to the Trust, for the benefit of Richard (hereinafter referred to as "Beneficiary") as hereinafter set forth.

2. Trust Administration and Distribution.

2.1 The property shall be held, managed, rented, sold, invested and reinvested by the Trustee who shall collect the income there from and, after deducting all charges and expenses properly attributable thereto, shall, at any time and from time to time, apply for the benefit of the Beneficiary, so much (even to the extent of the whole), without regard to the interest of the remainderment, of the net income and/or principal of this Trust as the Trustee shall deem advisable, in its sole and absolute discretion, subject to the limitations set forth below. The Trustee shall add to the principal of such Trust the balance of net income not so paid or applied.

2.2 It is the Grantor's intent to create a supplemental needs trust which conforms to the provisions of Section 7-1.12 of the New York estates, powers and trusts law. The Grantor intends that the Trust assets be used to supplement, not supplant, impair or diminish, any benefits or assistance of any federal, state, county, city, or other governmental entity for which the Beneficiary may otherwise be eligible or which the Beneficiary may be receiving. In keeping with the prior sentence and consistent with it, the Trustee is authorized to pay for the benefit of the Beneficiary from the income and principal of this Trust any sums that may be needed or useful in enhancing the lifestyle of Beneficiary, or for any costs or expenses he deems of extraordinary or compelling necessity. The Trustee shall take into

consideration in approving or rejecting any expenditures, the purpose of this Trust, its length of existence, any other resources available to Beneficiary, and the lifestyle right to reject any request for these funds that are not, in his opinion, needed to enhance the lifestyle of said Beneficiary, or do not represent extraordinary or exceptional needs.

2.3 None of the income or principal of this Trust shall be applied in such a manner as to supplant, impair or diminish benefits or assistance of any federal, state, county, city, or other governmental entity for which the beneficiary may otherwise be eligible or which the beneficiary may be received.

2.4. Notwithstanding the provisions of Paragraph 2B and 2C above, the Trustee may make distributions to meet the Beneficiary's need for food, clothing, shelter or health care even if such distributions may result in an impairment or diminution of the Beneficiary's receipt of eligibility for government benefits or assistance but only if the Trustee determines that (i) the Beneficiary's needs will be better met if such distribution is made, and (ii) it is in the Beneficiary's best interests to suffer the consequent effect, if any, on the Beneficiary's eligibility for or receipt of government benefits or assistance, provided, however, that if the mere existence of the Trustee's authority is actually exercised, this paragraph shall be null and void and the Trustee's authority to make such distributions shall cease and shall be limited as provided in Paragraph 2B and 2C above, without exception.

2.5 This Trust shall terminate upon the death of the Beneficiary. Upon the termination of the Trust, the Trustee is directed to pay to the State of New York or such other governmental entity such amount as shall be necessary to provide reimbursement for expenditures made for medical assistance for Beneficiary by the State of New York or such other governmental entity through Medicaid or equivalent benefit entitlement programs and the balance, if any remains, shall be paid to the distributees of Beneficiary then surviving after payment of all final debts, funeral expenses, estate taxes and other expenses of administration of the estate of the Beneficiary.

3. Additional Property. The right is hereby reserved to transfer and deliver or bequeath or devise by Last Will and Testament to the Trust, additional securities, money or other property for the benefit of the Beneficiary, and such additional securities, money or other property transferred and delivered to the Trustee shall become a part of the assets of the Trust.

4. Powers of Trust. The Trustee is hereby granted full and complete authority to exercise the following powers with respect to any property at any time comprising the Trust:

4.1 To invest and reinvest any funds in the Trust, in such property, except real property, as the Trustee may consider prudent and suitable. Authorized investments include life insurance policies and annuities, including policies and annuities on the life of the Grantor.

4.2 To sell, at public or private sale, mortgage, lease (even though the term of the lease may extend beyond the term of the Trust), and otherwise manage, subdivide and improve personal property and real property, including the rights below and above the surface of real property, including sales on credit, in such manner and at such manner and at such prices as the Trustee may determine.

4.3 To borrow money and pledge or mortgage any property for any lawful purpose.

4.4. To employ agents, brokers, accountants and attorneys, etc. and to pay their reasonable compensation and expenses.

4.5 To act in reliance upon any documents or other paper if believed by the Trustee to be genuine and to be signed and delivered by or on behalf of the proper person, firm or corporation without incurring liability for any action or inaction based thereon.

4.6 To exercise all other powers provided by law and not expressly prohibited herein.

5. Spendthrift Provision. The interest of the Beneficiary is principal and undistributed income shall not be subject to the claims of his or her creditors, or others, nor to legal or judicial process, and may not be voluntarily or involuntarily alienated, encumbered, anticipated or assigned.
6. Inspection of Records. The Trustee shall at all times hold her books open, and subject to inspection by the attorney or other legal representatives of Beneficiary.
7. No Assignment by Beneficiary. The beneficiary does not have the power to assign, encumber, direct, distribute or authorize distributions from this trust.
8. Trust Irrevocable. This Trust shall be irrevocable and the Grantor and Trustee shall hereafter be without power to alter, amend, revoke or terminate any of the provisions contained in this Trust Agreement, except that the Trustee shall amend the Trust, if necessary, to qualify it as a trust qualifying under 42 United States Code, Section 1396p(d)(4)(A), and the regulations and rules promulgated thereunder.
9. Trustee Permitted to Resign. The Trustee may resign at any time by delivering or mailing written notice of such resignation to Beneficiary or his legal representative. Such resignation shall take effect upon the date specified in such notice but not less than thirty (30) days after such mailing or delivery, and upon the date so specified all duties of the Trustee so resigning shall cease, except the duty to account and to turn over the Trust assets. The Trustee then in office can appoint a Successor Trustee(s) to serve after the death or resignation of the Trustee. Absent such an appointment, then



residing at New York, shall serve as Successor Trustee. The Successor Trustee shall have all of the rights, powers and duties as the original Trustee.

10. Accounting by Trustee. The Trustee shall provide an annual account to the Beneficiary and to his legal guardian, or other legal representative, and to the appropriate local Medicaid District, if and when the Beneficiary becomes a Medicaid recipient. A Trustee shall be entitled at any time to have judicial settlement of his, her or its account on notice to the Beneficiary, to his legal guardian, or other legal representative, and to the local Medicaid District if the Beneficiary has become a Medicaid recipient. Any such settlement agreement shall bind all persons, whether or not then in being, then or thereafter entitled to any portion of the Trust and shall effectually release and discharge the Trustee for the acts and proceedings so accounted for.
11. Notices. Any party shall give notice hereunder by personal delivery or by regular mail. The date of delivery or mailing shall constitute the date notice is given. Notice to a minor shall be given both to the minor and the minor's parent or guardian, if any.
12. Applicable Law. This Trust Agreement shall be construed and regulated by law of the United States of America, where applicable, and otherwise by New York in all respects.
13. Compensation. The compensation of the Trustee shall be determined in accordance with the laws of the State of New York as from time to time in effect.
14. Bond. No Trustee shall be required to furnish any bond or securities for the performance of his duties.
15. Provision as to E.P.T.L. 7-1.6 It is the further intent of the Grantor that no distribution be ordered in contravention of the intent of this trust and of 42 U.S.C. § 366(2)(b)(2)(iii)(A) and E.P.T.L. 7-1.12. This provision is intended to negate and eliminate any discretion granted to any Court pursuant to §7-1.6 of the E.P.T.L. The Grantor also intends that the funds provided by any third party be utilized for the "special needs" of the beneficiary. The Grantor intends that if the Trustee receives any contributions from the beneficiary, whether as an outright gift or pursuant to a Court order, that these Trust assets be protected by the terms of this Supplemental Needs Trust.
16. Notifications.
  - 16.1 The Trustee shall notify the appropriate Social Services district which has provided medical assistance to the beneficiary of the death of the beneficiary, and the Trustee shall verify a claim detail report of the total medical assistance provided to the beneficiary during the beneficiary's lifetime. The Trustee shall then satisfy such claim prior to making any other distributions pursuant to Article IIE, in accordance with federal and state law.

16.2 The Trustee shall notify the local Social Services District in advance of any transactions involving transfers from the trust principal for less than fair market value.

16.3 The Trustee shall notify the local Social Services District in advance of any transactions that substantially deplete the principal, in accordance with federal and state law.

IN WITNESS WHEREOF, the parties hereto have executed this trust agreement the day and year first written above.

\_\_\_\_\_  
Grantor, Trustee

State of New York            )  
  ) ss.:  
County of                        )

On the 29<sup>th</sup> day of March in the year 2002 before me, the undersigned, a Notary Public in and for said State, personally appeared            personally know or proved to me on the basis of satisfactory evidence to be the individual whose name is subscribed to the within instrument and acknowledge to me that he executed the same in his capacity, and that by his signature on the instrument, the individual, or the person upon behalf of which the individual acted, executed the instrument.

\_\_\_\_\_  
Notary Public

## APPENDIX V

### WHERE TO GET HELP IN NEW YORK STATE

#### PROTECTION AND ADVOCACY FOR THE DEVELOPMENTALLY DISABLED

CQCAPD Central Office

**New York State Commission on Quality of Care & Advocacy for Persons with Disabilities**

Division of Protection & Advocacy Administration

401 State Street

Schenectady, New York 12305-2397

Phone – 518-388-2892

Fax – 518-388-2890

Website: [www.cqcapd.state.ny.us](http://www.cqcapd.state.ny.us)

CQCAPD Regional Offices

#### **NEW YORK CITY REGION**

Counties served: Bronx, Kings, Manhattan, Queens, Richmond

New York Lawyers for the Public Interest, Inc.

151 West 30<sup>th</sup> Street, 11<sup>th</sup> Floor

New York, New York 10001-4007

212-224-4664

212-224-4570(TTY)

212-224-3692(Fax)

#### **UPPER HUDSON REGION**

Counties served: Albany, Columbia, Fulton, Greene, Montgomery, Rensselaer, Saratoga, Schenectady, Schoharie

Disabilities Law Clinic at Albany Law School

80 New Scotland Avenue

Albany, New York 12208

518-445-2328

518-434-8612(Fax)

Intake: Disability Advocates 518-432-7861

#### **NORTH COUNTRY REGION**

Counties served: Clinton, Essex, Franklin, Hamilton, St. Lawrence, Warren and Washington

Legal Aid Society of Northeastern New York, Inc.

PO Box 989, 100 Court Street

Plattsburgh, New York 12901

518-563-4022

518-563-4058 (Fax)

800-722-7380

Legal Aid Society of Northeastern New York, Inc.  
PO Box 648, 38 Gouverneur St.  
Canton, NY 13617  
315-386-4586  
800-822-8283  
315-386-2868 (Fax)

### **LOWER HUDSON REGION**

Counties served: Dutchess, Orange, Putnam, Rockland, Sullivan, Ulster and Westchester

Legal Services of the Hudson Valley  
4 Cromwell Place  
White Plains, New York 10601  
914-949-1305  
914-949-6213 (Fax)

Intake Office:

Legal Services of the Hudson Valley  
29 North Hamilton Street  
Poughkeepsie, NY 12601  
845-471-0058  
845-471-0244 (Fax)

### **CENTRAL REGION**

Counties served: Cayuga, Cortland, Herkimer, Jefferson, Lewis, Madison, Onondaga, Oneida and Oswego

Legal Services of Central New York, Inc.  
The Empire Building  
472 South Salina Street, Suite 300  
Syracuse, New York 13202  
866-475-9967 (Toll Free)  
315-475-3127  
315-475-2706 (Fax)

### **WESTERN REGION**

Counties served: Allegany, Cattaraugus, Chautauqua, Erie, Genesee, Livingston, Monroe, Niagara, Ontario, Orleans, Seneca, Steuben, Wayne, Yates and Wyoming

Western New York Advocacy for the Developmentally Disabled, Inc.  
590 South Avenue  
Rochester, New York 14620  
585-546-1700  
585-546-7069 (Fax)

Neighborhood Legal Services, Inc.  
295 Main Street  
Ellicott Square Building, Room 495  
Buffalo, New York 14203  
716-847-0650            716-847-0227 (Fax)

## **SOUTHERN TIER REGION**

Counties served: Broome, Chemung, Chenango, Delaware, Otsego, Schuyler, Tioga and Tompkins

Legal Services of Central New York, Inc.  
The Empire Building  
472 South Salina Street, Suite 300  
Syracuse, NY 13202  
866-475-9967 (Toll Free)  
315-475-3127  
315-475-2706 (Fax)

## **LONG ISLAND REGION**

Counties served: Nassau and Suffolk

Long Island Advocates, Inc.  
575 Underhill Blvd., Suite 118  
Syosset, NY 11791  
516-496-3606  
516-496-4158 (Fax)



**OFFICE OF MENTAL RETARDATION AND DEVELOPMENTAL  
DISABILITIES**

Office of the Commissioner  
44 Holland Avenue  
Albany, New York 12229  
518-473-9689  
518-474-3694 (TDD)  
518-474-1335 (Fax)

OMRDD Counsel's Office  
44 Holland Avenue  
Albany, New York 12229  
518-474-7700

**DEVELOPMENTAL DISABILITIES SERVICES OFFICES (DDSO)**

:

Bernard Fineson DDSO  
80-45 Winchester Blvd., Bldg. 12  
Queens Village, NY 11427  
718-217-4242  
718-217-4724 (Fax)  
County served: Queens

Brooklyn DDSO  
888 Fountain Avenue  
Brooklyn, NY 11208  
718-642-6000  
718-642-6282 (Fax)  
County served: Kings

Broome DDSO  
249 Glenwood Road  
Binghamton, NY 13905  
607-770-0211  
607-770-8037 (Fax)  
Counties served: Broome, Chenango, Delaware, Otsego, Tioga and Tompkins

Capital District DDSO  
OD Heck Developmental Center  
Balltown and Consaul Roads  
Schenectady, NY 12304  
518-370-7370  
518-370-7401 (Fax)  
Counties served: Albany, Fulton, Montgomery, Rensselaer, Saratoga, Schenectady,  
Schoharie, Warren and Washington

Central NY DDSO  
101 West Liberty Street  
Rome, NY 13442  
315-336-2300  
315-336-5456  
Counties served: Cayuga, Cortland, Herkimer, Lewis, Madison, Onondaga, Oneida and  
Oswego

Finger Lakes DDSO  
620 Westfall Road  
Rochester, NY 14610  
585-461-8500  
585-461-0618 (Fax)

Counties served: Chemung, Livingston, Monroe, Ontario, Schuyler, Seneca, Steuben, Wayne, Wyoming and Yates.

Hudson Valley DDSO  
Administration Building  
2 Ridge Road-PO Box 470  
Thiells, NY 10984  
845-947-6000  
945-947-6004 (Fax)

Counties served: Westchester, Orange, Rockland and Sullivan.

Long Island DDSO  
45 Mall Road  
Commack, NY 11725  
631-493-1700  
631-493-1803 (Fax)

Counties served: Nassau and Suffolk

Metro NY DDSO  
75 Morton Street  
New York, NY 10014  
212-229-3000  
212-229-0580 (Fax)

Counties served: Bronx and Manhattan

Staten Island DDSO  
1150 Forest Hill Road  
Staten Island, NY 10314  
718-983-5200  
718-983-9768 (Fax)

County served: Richmond

Sunmount DDSO  
2445 State Route 30  
Tupper Lake, NY 12986-2502  
518-359-3311  
518-359-2276

Counties served: Clinton, Essex, Franklin, Hamilton, Jefferson and St. Lawrence

Taconic DDSO  
26 Center Circle  
Wassaic, New York 12592  
845-877-6821  
845-877-9177 (Fax)  
Counties served: Columbia, Dutchess, Greene, Putnam and Ulster

Western NY DDSO  
1200 East and West Road  
West Seneca, NY 14224  
716-674-6300  
716-674-7488  
Counties served: Allegany, Cattaraugus, Chautauqua, Erie, Genesee, Niagara and Orleans.





## OMRDD REVENUE SUPPORT FIELD OFFICES

### ***Broome RSFO***

229-231 State Street-3<sup>rd</sup>  
Floor  
Binghamton, NY 13901  
607-771-7210  
607-771-1098 (fax)

**Counties:** Broome,  
Chenango, Delaware,  
Otsego, Tioga,  
Tompkins

### ***Capital District RSFO***

OD Heck DC-Bldg 12  
Balltown&Consaul Rds  
Schenectady, NY 12304  
518-370-2010  
518-370-2297

**Counties:** Albany,  
Fulton, Montgomery,  
Rensselaer, Saratoga,  
Schenectady, Schoharie,  
Warren, Washington

### ***Central/Sunmount***

101 W. Liberty Street  
PO Box 388  
Rome, NY 13440  
315-339-3440  
315-336-0407(Fax)

**Counties:** Cayuga,  
Cortland, Clinton,  
Essex, Franklin,  
Hamilton, Herkimer,  
Jefferson, Lewis,  
Madison, Oneida,  
Onondaga, Oswego, St.  
Lawrence

### ***Finger Lakes RSFO***

Newark DC-Vienna 4  
PO Box 70  
Newark, NY 14513  
315-331-7147  
315-331-0182 (Fax)

**Counties:** Chemung,  
Livingston, Monroe,  
Ontario, Schuyler,  
Seneca, Steuben,  
Wayne, Wyoming,  
Yates

### ***Hudson Valley RSFO***

3 Wilbur Road  
PO Box 470  
Thiells, NY 10984-0470  
845-947-6250  
845-947-6161 (Fax)

**Counties:** Orange,  
Rockland, Sullivan,  
Westchester

### ***Long Island RSFO***

415A Oser Avenue  
Hauppauge, NY 11788  
631-434-6109  
631-434-6085 (Fax)

**Counties:** Nassau,  
Suffolk

### ***New York City RSFO***

75 Morton Street-5<sup>th</sup> Flr  
New York, NY 10014-  
5798  
212-229-3343  
212-229-3095 (Fax)

**Counties:** Bronx, Kings,  
Manhattan, Queens,  
Richmond

### ***Taconic RSFO***

36 Fireman's Way  
Poughkeepsie, NY  
12603  
845-473-8210  
845-473-8204

**Counties:** Columbia,  
Dutchess, Greene,  
Putnam, Ulster

### ***Western New York***

West Seneca DC  
Building 70-2<sup>nd</sup> Floor  
1200 East & West Rd  
West Seneca, NY 14224  
716-675-8666  
716-675-8919

**Counties:** Allegheny,  
Cattaraugus, Chautauqua,  
Erie, Genesee, Orleans,  
Niagara

## **HOUSING ASSISTANCE**

### **Neighborhood Prevention Coalition of New York State**

303 Hamilton Street  
Albany, NY 12210  
518-432-6757

### **New York State Rural Housing Coalition**

350 Northern Boulevard  
Albany, NY 12204  
518-434-1314

## **NEW YORK STATE DIVISION OF HOUSING AND COMMUNITY RENEWAL**

119 Washington Avenue  
Albany, NY 12207  
518-432-0596

One Fordham Plaza  
Bronx, NY 10458  
718-563-5477

Ellicott Square Building  
295 Main Street, Room 438  
Buffalo, NY 14203  
716-847-3552

800 South Wilbur Avenue  
PO Box 1127  
Syracuse, NY 13201  
315-473-6930

## **CORPORATE GUARDIANSHIP PROGRAMS IN NEW YORK STATE**

NYSARC, Inc.  
393 Delaware Avenue  
Delmar, NY 12054  
518-439-8311

United Cerebral Palsy Association  
Of Nassau County, Inc.  
380 Washington Avenue  
Roosevelt, NY 11575  
516-378-2000

People, Inc.  
2128 Elmwood Avenue  
Buffalo, NY 14207  
716-874-5600

## ORGANIZATIONS THAT OFFER COMMUNITY AND/OR POOLED TRUSTS

### A PARTIAL LISTING

UJA/FECS of NY  
130 E. 59<sup>th</sup> Street-6<sup>th</sup> Floor  
New York, NY 10022  
212-980-1000

NYSARC, Inc.  
393 Delaware Avenue  
Delmar, NY 12054  
518-439-8311

ACLD-Adults & Children w/Learning  
and Developmental Disabilities, Inc.  
807 South Oyster Bay Road  
Bethpage, NY 11714  
516-822-0028

Community Living Services  
600 Bedford Road  
Mt. Kisco, NY 10549  
914-241-2527

YAI/National Institute for People with  
Disabilities  
460 West 34<sup>th</sup> Street  
New York, NY 10001-2382  
212-563-7474

Learning Disability Association (LDA)  
339 East Avenue, 4<sup>th</sup> Floor  
Rochester, NY 14604  
716-263-3323

Camphill Resident's Trust  
20 Triform Road  
Hudson, NY 12513  
518-851-9321

People, Inc.  
1219 N. Forest Road  
PO Box 9033  
Williamsville, NY 14231-9033  
716-634-8132  
1-800-7People

Disabled and Alone Life Services for the Handicapped, Inc.  
352 Park Avenue, South-11<sup>th</sup> Floor  
New York, NY 10010-1709  
1-800-995-0066

Lifetime Care Foundation for the Jewish Disabled  
4510 16<sup>th</sup> Avenue  
Brooklyn, NY 11204  
718-686-3275



## USEFUL WEBSITES

### NEW YORK STATE AGENCIES

Office for the Aging - [www.aging.state.ny.us/nysofa](http://www.aging.state.ny.us/nysofa)

Assembly, New York State - [www.assembly.state.ny.us](http://www.assembly.state.ny.us)

Commission on Quality Care & Advocacy for Persons with Disabilities – [www.cqcapd.state.ny.us](http://www.cqcapd.state.ny.us)

Developmental Disabilities Planning Council – [www.ddpc.state.ny.us](http://www.ddpc.state.ny.us)

Education Department – [www.nysed.gov](http://www.nysed.gov)

Health, Department - [www.health.state.ny.us](http://www.health.state.ny.us)

Housing and Community Renewal, Division of – [www.dhcr.state.ny.us](http://www.dhcr.state.ny.us)

Mental Health, Office of - [www.omh.state.ny.us](http://www.omh.state.ny.us)

Mental Retardation and Developmental Disabilities, Office of – [www.omr.state.ny.us](http://www.omr.state.ny.us)

Office of the Governor – [www.stae.ny.us/governor](http://www.stae.ny.us/governor)

Senate, New York State – [www.senate.state.ny.us](http://www.senate.state.ny.us)

Office of Temporary and Disability Assistance - [www.otd.state.ny.us](http://www.otd.state.ny.us)

### NEW YORK STATE NOT-FOR-PROFIT ORGANIZATIONS

NYS ARC – [www.nysarc.org](http://www.nysarc.org)

NYS UCP – [www.ucp.org](http://www.ucp.org)

NYS Association of Community and Residential Agencies – [www.nysacra.org](http://www.nysacra.org)

NYS Rural Housing Coalition, Inc. - [www.ruralhousing.org](http://www.ruralhousing.org)

Neighborhood Preservation Coalition of NYS – [www.npcnys.org](http://www.npcnys.org)

Disabled and Alone Life Services – [www.disabledandalone.org](http://www.disabledandalone.org)