

# Family Information Brochure

## *The NYSARC Trust*

*and  
Trustees' Services*



A service provided for the benefit of people who have mental retardation or other developmental disabilities and their families in furtherance of NYSARC's continuing mission.

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**The  
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Trustees' Services**

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**The NYSARC Trust**  
and Trustees' Services

***Trustees***

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*Please call the NYSARC, Inc. office at (518) 439-8311 if you have any questions regarding the information provided in this booklet.*

***Nothing contained herein shall constitute legal advice. Please consult an attorney prior to signing any trust documents.***

## GLOSSARY OF TERMS

### **Beneficiary:**

The person with a disability for whose benefit a trust or insurance policy has been established. The beneficiary must have a diagnosis of mental retardation or other developmental disability in order to be eligible to establish an account with The NYSARC Trust.

### **Bequest:**

A gift of personal property made through a will.

### **Corpus:**

Corpus is Latin for “body”, but here it means the money itself, or the bonds, stocks, life insurance policies or other assets you wish to give to the Trustee for the benefit of the beneficiary.

### **Devise:**

A gift of real property made through a will.

### **Developmental Disabilities:**

A person having an impaired ability to understand and appreciate the nature and consequences of decisions, and which result in such person being incapable of managing himself or herself and /or his or her affairs by reason of such developmental disabilities and that such condition is permanent in nature or likely to continue indefinitely, and whose disability:

- 1) is attributable to cerebral palsy, epilepsy, neurological impairment, autism or traumatic head injury;
- 2) is attributable to any other condition of a person found to

## GLOSSARY OF TERMS

be closely related to mental retardation because such condition results in similar impairment of general intellectual functioning or adaptive behavior to that of mentally retarded persons; or

- 3) is attributable to dyslexia resulting from a disability described in subdivision one or two of this section or from mental retardation; and
- 4) originates before such person attains age twenty-two provided, however, that no such age of origination shall apply for the purposes of this article to a person with traumatic head injury.

*(As defined by Section 1750-a of the Surrogate's Court Procedure Act)*

### **Discretionary Powers:**

Powers that provide a trustee many options in managing trust assets in order to accommodate varying situations.

### **Donor, Grantor, Settlor:**

The person who creates the trust. Parents are most frequently the ones who establish a trust for the benefit of their child with a disability.

### **Executor/Executrix:**

The person responsible for collecting, maintaining, and distributing the assets of an estate in accordance with the terms of the will. A male is referred to as an Executor and a female is referred to as an Executrix.

## GLOSSARY OF TERMS

### **Fiduciary:**

A person or institution that manages money or property for another and who must exercise a standard of care in such management activity which is imposed by law or contract (e.g. a Trustee).

### **Grantor, Settlor, Donor:**

The person who creates the trust. Parents are most frequently the ones who establish a trust for the benefit of their child with a disability.

### **Inter vivos Trust:**

A trust which is established by the grantor during his or her lifetime and which becomes effective during the lifetime of the grantor. An Inter vivos trust can terminate on the death of the grantor, during the grantor's lifetime or at some other designated time.

### **Intestate:**

Dying without leaving a valid will. If a person dies without a will, the courts will divide his/her assets according to State law.

### **Irrevocable Trust:**

A trust that the settlor or grantor cannot alter or terminate after it has been created.

### **Mental Retardation:**

Sub average intellectual functioning which originates during the developmental period and is associated with impairment in adaptive behavior. (As defined in Mental Hygiene Law, Article 1.03).

## GLOSSARY OF TERMS

### *Pooled Fund:*

The pooling of monies by multiple beneficiaries for investment purposes. A pooled fund can be established and managed by a non-profit association, such as NYSARC, Inc. Separate accounts for each beneficiary are maintained.

### *Remainderman:*

The person(s) who receives the remaining assets of a trust at the trust's termination.

### *Self-settled Trust:*

A Self-settled Trust is a type of Supplemental Needs Trust which is an inter vivos or living trust in which the beneficiary's own assets are used to fund the trust. Typically the monies used to fund the trust are received by a person with a disability as a result of a court order, inheritance, life insurance payout, or a medical malpractice or personal injury action.

This type of trust is established for the benefit of an individual with disabilities and is funded by that person's own assets. This is commonly referred to as a "payback", "self-settled" or "OBRA Trust" which was authorized by federal legislation entitled the Omnibus Budget Reconciliation Act of 1993. Funds remaining in this type of trust at the beneficiary's death must be repaid to the state for medicaid costs paid to or on behalf of the beneficiary, unless the trust, is a "pooled" Self-settled Trust, described below.

In addition to authorizing "payback" trusts, federal and state legislation also authorized the establishment of pooled, Self-settled Supplemental Needs Trusts, often referred to as "pooled trusts." This second type of trust must be created and managed by a non-profit corporation. NYSARC has created two such pooled

## GLOSSARY OF TERMS

trusts (The NYSARC, Inc. Community Trusts), which are available to residents of New York State who have a disability and who have resources of their own that can be used to fund the trust. Funds remaining in a pooled trust at the death of the beneficiary must remain with the trust to be used for the benefit of other persons with disabilities.

### **Settlor, Grantor, Donor:**

The person who creates the trust. Parents are most frequently the ones who establish a trust for the benefit of their child with a disability.

### **Supplemental Needs Trust (SNT):**

A trust which provides funds to a fiduciary for the benefit of a person with developmental disabilities. The assets of a Supplemental Needs Trust (SNT) are not considered as “available assets or resources” for the purpose of determining whether a person shall be eligible to receive governmental benefits. SNT funds are intended to supplement and not replace governmental benefits programs such as Medicaid and SSI.

The purpose of an SNT is to enhance the beneficiary’s quality of life by enabling the purchase of additional support services, social and recreational opportunities, advocacy, guardianship as well as medical services and equipment that are not otherwise covered or adequately provided through state and federal benefit programs.

An SNT may be funded by a third party, such as a parent, grandparent, friend or relative. This type of trust is commonly referred to as a “Third Party Trust.”

According to New York State’s Estates, Powers & Trusts Law (“EPTL”) 7-1.12, a third party can establish an inter vivos or

## GLOSSARY OF TERMS

testamentary Supplemental Needs Trust for the benefit of a person with a severe and chronic or persistent disability whose disability is expected to, or does require, long-term specialized services.

A Third-Party trust is to be distinguished from a Self Settled Trust, because upon the death of the person with a disability, the remainderman can be whomever the creator of the Trust determines.

### *Testamentary Trust:*

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

### *Trust:*

A legal device created by an individual, called the “settlor, grantor or donor”, who places money or other property in the hands of a fiduciary (the “trustee”). The money or property placed in the trust can be used only for the benefit of a certain named individual (the “beneficiary”).

### *Trustee:*

A person or a legally established and permitted entity who has legal title to property, holds it in trust for the benefit of another and owes a fiduciary duty to the beneficiary.

## FREQUENTLY ASKED QUESTIONS

### ***Is a Last Will and Testament necessary if I have created an Inter Vivos Trust?***

Yes. Even if a trust has been established and funded during an individual's life, the person who established the trust may have other assets, or not know exactly what assets they will own when they die. These other assets should be disposed of by a Last Will and Testament. Otherwise, the beneficiary of the trust may inherit these assets through intestacy, which could interfere with that individual's government benefits.

### ***Will money, personal property or real property left directly to a person with a disability affect his/her public assistance benefits?***

Yes. Any money, personal or real property will be considered resources, which may result in the loss of government benefits.

### ***Should money be left in a bank account IN TRUST for a person with disabilities?***

No. Such a bank account arrangement is known as a "Totten Trust". A problem with this type of banking arrangement is that upon the death of the person named on the bank account the account will be treated as if it were left directly to the person with a disability. This could interfere with the individual's government benefits.

### ***Does NYSARC, Inc. need to be named Guardian of the person of the beneficiary in order to use The NYSARC Trust?***

No. While some of the people for whom NYSARC, Inc. has been appointed Guardian of the person are also beneficiaries of a fund administered by **The NYSARC Trust**, there is no requirement for such an arrangement. In many cases a family member is the Guardian of the person and **The NYSARC Trust** serves as a Trustee of the property.

### ***If a gift is made to The NYSARC Trust, can additional money or property be added at a later time?***

Yes. Additional monies or property may be added to the Funds

## FREQUENTLY ASKED QUESTIONS

at anytime by gifts from relatives or friends, or through a bequest in a Last Will and Testament.

### ***Who can contribute to The NYSARC Trust on behalf of a Trust beneficiary?***

Any parent, relative or friend of a person with disabilities can give or leave money for the benefit of the person for whom a fund has been established.

### ***What is the minimum amount of money that is needed to setup an account under The NYSARC Trust Unrestricted Fund?***

The Trustees will accept any funding amounts of \$25,000 or more. In the event a gift is less than \$25,000, the Trustees have the discretion to make special arrangements.

### ***Can property be given to The NYSARC Trust?***

Yes, tax exempt securities and even certain types of personal property, such as works of art or real property, can be given to the Unrestricted Fund or to the Exempt Fund subject to approval by Trustees.

### ***Can The NYSARC Trust be designated as the beneficiary of a Life Insurance Policy for the benefit of a person with disabilities?***

Yes. This is one of the best ways to ensure that adequate funds will be available for the benefit of a person with disabilities.

### ***Who manages The NYSARC Trust?***

NYSARC, Inc. appoints a minimum of five and maximum of nine individuals, who may be attorneys, financial planners, other professionals and parents of individuals with disabilities to act as Trustees. All monies received by the Trustees will be professionally co-managed by a financial institution.

## FREQUENTLY ASKED QUESTIONS

### ***What assurance is there that the income and principal will be payable for the benefit of the person with a disability?***

The ultimate responsibility for payment to each beneficiary rests with the Trustees. The Trustees, however, may rely on guidance from the Guardian of the beneficiary (if one is appointed) to determine the needs of the person. All principal is invested prudently to ensure the availability of funds to the beneficiaries.

### ***Are the Trustees required to file any accountings?***

The Trustees must annually submit a financial accounting to the Executive Committee of NYSARC, Inc. This accounting is audited by a certified public accountant who is selected by the Executive Committee of NYSARC, Inc.

### ***Who receives reports of the beneficiary's accounts?***

Every month, the Trustees prepare and submit to the Guardian of the person of each Beneficiary or, if no Guardian has been appointed, to such relative of the Beneficiary as the Trustees shall designate or the agency providing services, a statement of value of the share of the trust fund held for the Beneficiary, the income earned during the year, and the manner and amounts in which both income and principal were expended on behalf of the Beneficiary.

### ***Is the gift or bequest tax deductible?***

Gifts or bequests to the "Unrestricted Fund" are not currently tax deductible. Direct gifts or bequests to the "Exempt Fund" may be eligible for income or estate tax deductions. Check with your tax preparer or attorney concerning any income or estate tax planning.

## FREQUENTLY ASKED QUESTIONS

### ***Can arrangements be made so that the Fund will pay for funeral expenses?***

Yes. Families are strongly encouraged to provide funds for funeral and burial expenses. In the absence of any financial arrangements, the Trustees are authorized to use their discretion in distributing funds for reasonable funeral and burial expenses unless the governing instrument states otherwise.

### ***How is a gift or bequest to the “Unrestricted Fund” properly worded?***

We strongly advise that an attorney be consulted when considering a gift or bequest to the Unrestricted Fund to ensure correct and appropriate wording.

# The NYSARC Trust and Trustees' Services

NYSARC, Inc. (formerly known as the New York State Association for Retarded Children, Inc.), is a family-based not-for-profit, New York State corporation founded in 1949. Its mission is to assist and support children and adults with mental retardation and other developmental disabilities and their families in areas such as education, employment, family support, recreation, advocacy, housing and guardianship. NYSARC, Inc. is committed to enhancing not only the desired quality of life for persons with disabilities and their families, but in promoting autonomy, maximizing the development of individual skills, and fostering their integration into the community.

At present, NYSARC, Inc. has chapters located in almost every county in New York State. These local chapters provide a host of programs, supports and services throughout the State of New York.

In response to growing concerns commonly expressed by parents and others for safeguarding the personal and financial future of persons with mental retardation and other developmental disabilities, NYSARC, Inc. established **The NYSARC Trust** (formally known as the New York Retardate Trust) on July 19, 1972.

### ***What Is The NYSARC Trust?***

The NYSARC Trust currently consists of two active, separate and distinct funds (The Unrestricted Fund and The Exempt Fund). The Unrestricted Fund enables parents, relatives and friends to leave modest to large sized sums of money or other property for the benefit of a person with a developmental dis-

## OVERVIEW

ability. Money or property can be transferred to this fund either through an inter vivos transfer during the Grantor's life or through a testamentary transfer at death. The Exempt Fund, was established primarily to benefit and support NYSARC, Inc.'s Corporate Guardianship Program

NYSARC has operated a trust service continuously since 1972. Its purpose is to provide a vehicle for leaving funds to children and adults with mental retardation or other developmental disabilities without negatively affecting their eligibility for government benefits, such as SSI, Medicaid, and state or federally funded residential and day programs.

One of the main benefits of a Supplemental Needs Trust is to enhance the quality of life for a beneficiary by providing for the purchase of additional support, services, therapies and other items that are not covered by nor provided adequately for by available government programs. The NYSARC Trust provides a financial vehicle to meet both the anticipated and unforeseen future needs of persons with disabilities.

Experience has shown that parents who know the capabilities and needs of their child may be unaware of the legal devices available to meet those needs. Attorneys who may be knowledgeable in estate planning may be unaware of the differing needs of persons with disabilities. Only through a realistic appraisal of the individual's needs and the retention of an attorney knowledgeable and experienced in estate planning for persons with disabilities can a parent, sibling or other relative be assured that his/her family member will receive the best available assistance and protection for their financial future.

Estate planning for persons with disabilities can range from simply creating a Last Will and Testament containing special trust provisions, to a complex estate planning arrangement involving a will, an inter vivos trust, a life insurance trust, other

## OVERVIEW

estate planning techniques, and even guardianship planning. At a minimum, families should take steps to secure the financial future of their loved ones. The NYSARC Trust may be a vehicle to be considered in formulating an appropriate estate plan.

The NYSARC Trust provides a means by which parents, family members and friends of persons with mental retardation or other developmental disabilities can avoid extraordinary expenses of trust administration during their lifetime. The NYSARC Trust does not pay any commissions to its Trustees for their services. This allows a family member with developmental disabilities to benefit more fully from the income and principal contributed to the Trust without having to spend precious resources on Trustee services.

Another distinctive feature of the NYSARC Trust is that the Grantor may select who will receive the remainder of any assets held in the beneficiary's trust account upon the death of the person with disabilities (the beneficiary) subject to certain provisions which are discussed later. In the absence of any designation of the remainder, any remaining balance will be made payable to The NYSARC Trust-Exempt Fund of the Association to be used for the benefit of its Guardianship Program.

A third significant benefit of using the NYSARC Trust is that the Trustees are a group of highly dedicated individuals who possess a working knowledge of the needs and abilities of persons with developmental disabilities. Such expertise provides a helpful contribution to a beneficiary's overall quality of life.

Furthermore, each gift or bequest, regardless of size, receives the same investment management supervision from the date of contribution. For parents that do not have other children or

## OVERVIEW

relatives that could act as an independent Trustee, the **NYSARC Trust** provides a level of continuity and financial security for their loved ones.

In summary, there are many benefits associated with using the **NYSARC Trust** to meet the unique needs of persons with disabilities, including:

- 1) the provision of Trustee services to administer funds of modest size;
- 2) continuity of financial management;
- 3) Trustees who are knowledgeable of the needs of persons with mental retardation and other developmental disabilities;
- 4) no Trustee commissions; and
- 5) flexibility to decide who shall be the remainder beneficiary(ies) upon the death of the disabled family member.

## OVERVIEW

### ***Unrestricted Fund***

*(Documents Available Upon Request)*

The Unrestricted Fund accepts gifts or bequests, both testamentary and inter vivos, of \$25,000 or more from parents, relatives or friends for the benefit of a designated beneficiary with mental retardation or other developmental disabilities. The entire income and principal from such gift or bequest may be paid or applied as directed by the donor either monthly, quarterly or annually at the discretion of the Trustees for the benefit of a person with developmental disabilities. The Trustees make these distribution decisions in consultation with the guardian, if any, or interested family members or service providers. However, it is important to remember that the ultimate decision with respect to distributions remains in the sole discretion of the Trustees. This discretion may be subject to any limiting provisions contained in the instrument used to make the gift or bequest. Additionally, the Trustees may pay any Court approved fees and reasonable out-of-pocket expenses incurred by any Court appointed Guardian in the administration of the Guardian's duties.

Upon the death of the beneficiary in lieu of commissions being charged during the existence of the account, \$25,000 of the remaining principal, or the balance thereof if less than \$25,000, shall be paid to the Exempt Fund (described in a subsequent section) for the benefit of the Guardianship Program of NYSARC, Inc. The excess of any principal amount over \$25,000 will be paid to whomever the grantor directs in the trust instrument or will, which might include the Exempt Fund, surviving children, relatives, NYSARC or other organizations that the Grantor may have designated.

## OVERVIEW

### ***Exempt Fund***

*(Documents Available Upon Request)*

The Exempt Fund is a fully tax exempt fund that was created for the sole benefit of the Guardianship Program of NYSARC, Inc. Gifts or bequests to this Fund are tax deductible to the donor for income, gift and/or estate tax purposes to the extent permitted by law. Please consult your tax advisor for advice concerning contributions to this Fund. All monies contributed to this Fund are used to support the Guardianship Programs, and to meet the expenses of administering the Funds, which include bookkeeping and accounting services as well as Trustee expenses.

NYSARC, Inc., through its chapters, initially provided more than \$50,000 for the establishment of this Fund in order to ensure that no expenses other than investment expenses of the Unrestricted Fund would be chargeable against any of the income earned for the various individual beneficiaries.

### ***Trustees***

A board of no more than nine (9) Trustees (which may include attorneys, financial planners, parents and other professionals) is charged with the administration of the Trust. The Trustees are appointed by the Executive Committee of the Board of Governors of NYSARC, Inc. The Trustees carry out the policies set forth in the trust agreements and work closely with NYSARC, Inc.'s professional staff as well as with employees of other agencies operating similar programs. An annual budget is prepared by the Trustees and the Funds of the NYSARC Trust are audited annually by a Certified Public Accountant. In addition, the Trust, as required by law, files all necessary annual statements and reports with the relevant federal and state governmental agencies. While the Trustees are not guardians, they have a fiduciary duty to administer the Trust and make

## OVERVIEW

disbursement decisions in the best interest of the Trust beneficiaries. All decisions made by the Trustees are subject to the terms of the Trust and are further subject to any specific terms of a particular gift or bequest made by the Grantor or included in a Last Will and Testament giving rise to any bequest. The policy of the Trustees is to make the wisest possible use of the funds at their disposal for the benefit of individuals with mental retardation or other developmental disabilities.

### ***The NYSARC Inc. Community Trusts*** *(Documents Available Upon Request)*

In addition to the NYSARC Trust previously referenced in this document, NYSARC, Inc. offers persons with disabilities and their families other Trust planning tools, such as the NYSARC, Inc. Community Trusts. These Trusts are pooled trusts created and managed by NYSARC, Inc., which qualify as Supplemental Needs Trusts for the benefit of people with disabilities, and which are funded with the personal assets of the person with disabilities. (They are typically referred to as a Self-settled Supplemental Needs Trusts).

The purpose of a Self Settled Supplemental Needs Trust is to permit an individual with disabilities to protect personal assets while remaining eligible for governmental assistance programs. Without a Supplemental Needs Trust an individual with disabilities could be forced to spend the majority of his/her assets in order to remain eligible for governmental assistance. The Community Trusts provide a vehicle for an individual who receives an outright inheritance, an award from a lawsuit, or lump sum payment from Social Security, or income from other sources to effectively shelter that money, while remaining fully eligible for governmental benefits.

If you or your attorney would like further information about the NYSARC Inc. Community Trusts, please contact the NYSARC office at (518) 439-8311.

## CONCLUSION

### *Conclusion*

The use of a trust fund can be an effective tool in estate planning for families with young or adult children with disabilities. This is especially true when individuals with developmental disabilities rely on government entitlement programs to meet their basic needs. The use of these trust vehicles will assist in supplementing any public benefits which are being received. The additional financial security derived from using these long term planning tools can provide a person with developmental disabilities with a greater opportunity to lead a more complete and fulfilled life.





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