

The Arc of New Jersey presents

**LEGAL CONSIDERATIONS IN
PLANNING FOR
INDIVIDUALS WITH
DISABILITIES**



**A GUIDE FOR
SIBLINGS**

by

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The
Arc
OF NEW JERSEY

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The Arc of New Jersey is the largest non profit advocacy organization for people with mental retardation and their families in New Jersey. Started in 1946 by a parent of a child with mental retardation, we are today still a parent directed membership organization. More than 6,000 families make up the current membership of The Arc of New Jersey. We are affiliated with The Arc, a national organization on mental retardation with more than 1000 chapters and 140,000 members nationwide. The Arc of New Jersey is comprised of a state office and 20 local county chapters providing services in 21 counties.

The state office of The Arc of New Jersey is responsible for general statewide activities such as family advocacy, public relations, community outreach, information and referral, communications and publications, local chapter support, and public policy analysis and advocacy.

The local county chapters of The Arc of New Jersey provide a wide variety of direct services for people with developmental disabilities and their families.

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A Note from Ted Stieve, President of The Arc of New Jersey

Friends,

The Arc of New Jersey is pleased to be working with Hinkle & Fingles, Attorneys at Law to bring you this special booklet. This guide is for all siblings of individuals with a developmental disability who are preparing to take on more responsibility in the care of their brother or sister, and will help educate family members on topics such as special education, adult services, guardianship and estate planning, and income and medical benefits.

I have been an active volunteer with The Arc for more than 20 years. Why? My late brother, John, the youngest of my three brothers, had mental retardation. John lived at home with our parents into his adulthood. Our parents enriched his life, and were themselves volunteers in the early movement of The Arc. They passed within two years of one another. Suddenly, John became the responsibility of the brothers. What now? For three disruptive years John relocated between brothers, experienced respite care and a skill development home. Finally, in 1983 he took up residence at a new group home operated by The Arc of Monmouth. John spent 17 happy and fulfilling years in his new home. Then, however, his health began to fail. I became his guardian and was involved in daily decisions requiring relevant information from a melange of agencies, doctors and health insurance providers. Armed with this information in advance, the process would have been far less stressful.

For years, information has been mostly directed to parents. This sibling support project will help siblings to take on the role of caregiver and advocate. I hope you will take advantage of this special guide. I urge you not to wait until it is too late: start planning for the future today.

I look forward to working with all of you in enhancing the lives of our loved ones with a developmental disability.

Ted Stieve
President
The Arc of New Jersey

INTRODUCTION

Among all relationships, the relationship between siblings is the longest lasting. In the vast majority of cases, siblings are there for each other long after the parents are no longer available due to death or incapacity.

In the past, information available to families of individuals with disabilities has focused almost exclusively upon issues of importance to parents. This approach has failed to recognize the primary role that siblings often play in the lives of individuals with disabilities.

Siblings of individuals with disabilities face unique challenges from the earliest stages of their lives. Young children can be frightened or bewildered by their sibling's disabilities. There can be resentment because of the increased parental attention that the sibling with disabilities receives. As they grow older and become more socially aware, children can become embarrassed or ashamed of their sibling's disabilities, and may even be teased or taunted themselves.

As the family grows older, concerns arise in their minds about whether they will have to financially support their sibling with disabilities, whether the sibling with disabilities will need to live with them in their home, or whether the increased caregiving demands will interfere with the achievement of their own goals and dreams.

Uncertainty about how their sibling's needs will be met after the parents are unable to provide care is perhaps the most anxiety-provoking issue to the non-disabled siblings.

These concerns are natural and must be addressed. Parents can go a long way towards ensuring that all of their children, both disabled and non-disabled alike,

*At some point, most
siblings of individuals
with disabilities
begin to wonder:
“Who will care for my
brother or sister when my
parents are gone?”*

manage these issues and go on with their lives in a comfortable, secure manner after parents are gone.

For a family in which there is a child with disabilities, the parents should attend to, among other things, the following questions:

- *Who will make decisions on behalf of my child with a disability after I am gone?*
- *What needs to be done to ensure that a decision-maker is legally empowered to act on my child's behalf after my child reaches adulthood?*
- *What services are available to make sure that my child with a disability is provided an appropriate job or day program?*
- *How can I ensure my child has a place to live that can meet his or her needs in a safe environment?*
- *How can I make sure my child's supplemental, personal, and recreational needs are covered?*
- *What steps do I need to take now to make sure that services are available without delay when the need arises?*
- *How can I provide financial security for my child with a disability without jeopardizing vital services and benefits?*
- *How do I provide funds for the benefit of my child with a disability without subjecting those funds to claims by the government for repayment for services that my child receives?*

Whether or not parents have addressed these issues, these are the same types of issues siblings will encounter as responsibility for care transfers. If parents have not addressed these issues, siblings should persuade parents to attend to them before they are no longer able to do so.

What follows is a brief guide to services for people with disabilities and a summary of things both parents and siblings can do to plan for the future and ensure the continuation of services without interruption.

Services for
individuals with
disabilities can be
broken into four broad
categories:

- (1) special education services for children under twenty-one;
- (2) adult services for those over the age of twenty-one;
- (3) guardianship and estate planning considerations; and
- (4) income and medical benefits.

SPECIAL EDUCATION

It is unlikely that siblings of individuals with disabilities will be directly involved in the educational needs of their brother or sister. Nevertheless, siblings should at least have a basic understanding of special education rights and obligations. Children between the ages of 3 and 21 with disabilities severe enough to negatively affect learning are entitled to special education services. This is a federally mandated program available in all states. Special education in New Jersey is the responsibility of local school districts, with oversight provided by the New Jersey Department of Education.

School districts are responsible to identify, evaluate, and then classify children with disabilities as eligible for special education and related services. State regulations set out timelines and the methods to accomplish this, along with administrative procedures to resolve disputes.

The thrust of the federal law is that each child must receive a program that meets his or her unique and individual needs. School districts must develop annually a written Individualized Education Program (IEP) outlining the services to be provided with measurable goals and objectives. For some children, the IEP might involve classroom modification or a few sessions of individual instruction or therapy. Other children might require placement in a specialized class or even placement in a private school which specializes in serving children with

a particular type of disability. These schools can provide services on a day or a residential basis. Depending on need,

School evaluations can be helpful to determine eligibility for adult services and other government assistance programs.

children might be entitled to an extended year program over the summer months.

Schools are required to create an extensive number of documents evaluating a child's special education needs as well as the child's progress in school. These evaluations and other records can often be helpful later in life to determine eligibility for adult services and other government assistance programs. Therefore, parents should keep evaluations and IEPs provided by the school at least until adult services and social security benefits (discussed later) are secured. Doing so will greatly help the non-sibling with disabilities's efforts on behalf of their brother or sister.

ADULT SERVICES

Unlike special education, services for adults with disabilities are not federally mandated and are not always free.

The New Jersey Division of Developmental Disabilities (DDD) provides day and residential services to people with developmental disabilities, such as mental retardation, cerebral palsy, autism, and other severe, chronic impairments originating prior to age 22, usually excluding mental illness.

Day Services

Individuals with developmental disabilities should be provided with constructive, structured activities during the day. These services are available through DDD, or in some cases, the Division of Vocational Rehabilitation Services (DVRS). Depending upon one's preferences and ability levels, these services can range from placement in a sheltered workshop to the provision of job coaching and other supportive services in a community-based employment setting.

Keep in mind that there may be a waiting list for some services, so it is important to apply early. If possible, an application for services should be completed five years before the individual graduates from school.

Ideally, families should ensure these services are in place upon graduation. If this is not possible, then it is critical that these services are in place before parents are no longer capable of providing care.

Ideally, families should ensure these services are in place upon graduation. If this is not possible, then it is critical that these services are in place before parents are no longer capable of providing care. However, if parents have not done so before they are gone, then siblings must immediately seek to acquire these services for their brother or sister. In some cases, an adult with a disability may be entitled to an emergency day placement.

Residential Services

DDD is the primary residential placement source for individuals with developmental disabilities in New Jersey. Placement options range from group homes, in which several individuals with disabilities live together and receive around-the-clock care, to supervised apartments and supportive living pro-

grams, in which an individual with disabilities lives on his or her own and receives training and periodic visits from support staff. It may also be possible to secure funding for services to allow an individual to remain in his or her own home. However, securing the appropriate placement takes time.

Long waiting lists exist, which can run five to seven years, or longer. In order to be residentially placed, one must be in the top or 'priority' category of the waiting list. Although immediate placement may be available in the case of an emergency, such as upon the death or incapacity of the parents, it is important for siblings to encourage parents to seek assignment to the priority category of the waiting list while they are still healthy. Doing so will increase the number of options available at the time residential placement is made and will help avoid a crisis.

The Division of Mental Health Services (DMHS) provides a similar array of services to people with mental illness. Priority for community residential services is given to people eligible for discharge from state psychiatric hospitals;

but clients can go directly from home into a supervised living arrangement. Parents often believe that the sibling without a disability will allow their brother or sister to come live with them after they (the parents) die. Parents should be mindful however, of the needs of *both* the child with and without the disability and should understand that this is often not a realistic option.

Children without disabilities often have families and work responsibilities of their own that make providing care to an adult with a disability nearly impossible. For example, a non-disabled sibling may be required to relocate to another part of the country for work. Additionally, spouses and children of the non-disabled sibling can become resentful of the demands placed on their family when faced with this situation. Parents must keep in mind the effect that such an arrangement will have on the adult child with a disability as well, who may be better served by living apart from family and as independently as possible.

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life-long care to their adult sibling with a disability.

Parents owe it to their children both with and without disabilities to carefully plan for the future.

Finally, parents and siblings should know that many state agencies are entitled under state law to seek reimbursement for the costs of the services that are provided. Currently, in New Jersey, the only service for which reimbursement is sought is residential placement.

Reimbursement can be sought from parents of children under the age of eighteen; but after that age, the government can only seek reimbursement from the individual receiving services.

Therefore, it is important to ensure that the assets of the sibling with disabilities are sheltered in the correct way to limit exposure and help avoid the need to pay for services that would otherwise be provided free by the government.

GUARDIANSHIP

No one topic will confront non-disabled siblings more than that of guardianship. After parents are gone, the brother or sister of a person with a disability is the next person best suited for this role. It is important, therefore, for the sibling to have a basic idea of the guardian's responsibilities.

In New Jersey, the age of majority is eighteen. As a result, in the eyes of the law, whether someone has a severe disability or not, that person is legally permitted to make his or her own decisions at the age of 18. Therefore, if due to a disability, a person is not capable of making his or her own decision, it is necessary to secure the judicial appointment of a guardian.

A guardian is someone who makes decision on behalf of another person who cannot make decisions independently. A guardian can also manage the property of a person with a severe cognitive disability. A *guardian of the person* usually has the power to make decisions concerning living arrangements, day programs, medical care, and other personal decisions. A *guardian of the property* usually has the power to make decisions regarding whether and how to sell, trade, or invest property. However, a guardian of the property does not have power over any assets

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held in trust unless the guardian is also the trustee.

In order to have this authority, a court must first find that the person cannot make decisions about himself or his property. If a court determines that he cannot, then it will appoint someone to take on this responsibility. In most cases, this will be one or both parents. However, the court may also appoint a brother or sister to serve as guardian with the parents, or alone after the parents have died. Parents can also appoint a successor guardian in their will. Parents can also temporarily delegate guardianship through a power of attorney.

The obligation of the guardian is to make sure that the person with a disability is safe and to make decisions in the best interest of the person under guardianship. The guardian does not bear any risk for the person's acts or debts, and is not un-

der a legal obligation to provide direct care to the person. Therefore, there is no downside to serving as someone's guardian.

Parents and siblings alike should understand that the non-disabled sibling will

likely one day serve as their brother's or sister's guardian. Parents should discuss this issue long before the need arises, and help the non-disabled sibling feel more confident in taking on this responsibility.

MEDICARE AND MEDICAID

Medicare and Medicaid can be very confusing.

Medicare is provided to people 65 and over, to Social Security Disability Income (SSDI) recipients and permanently disabled Social Security recipients. Medicare is divided into two parts. Part A covers hospital and limited nursing care. Part B, which requires an extra premium, covers physician services, as well as a variety of therapies and other items. Medicare also has co-payments and deductibles.

Medicaid, in theory, covers all medical expenses and there are no deductibles and co-payments. However, in practice, a number of physicians will not accept it. Medicaid will also pay for institutional care in nursing facilities and in some cases in non-specialized placements to people with disabilities.

Eligibility for Medicaid is similar to that of SSI. The applicant must have monthly income of approximately \$500 or less and no more than \$2,000 in countable assets. There are no income and resource tests for Medicare. Also, like Supplemental Security Income (SSI) income and resources of parents will be deemed to a child under age eighteen. However, Medicaid has the authority to waive deeming rules if a child has medical needs so extraordinary that if without Medicaid, institutionalization would be necessary. This is known as a Community Care Waiver, which is administered by the New Jersey Division of Developmental Disabilities.

For more on SSI and SSDI, see page 17.

ESTATE PLANNING CONSIDERATIONS

Most parents want to leave assets to their children when they die. However, if a person with a disability receives assets, the results can be disastrous. The person will lose Medicaid and SSI, and the assets may also be subject to recoupment by Medicaid, or by the State of New Jersey if the person is receiving residential services.

Based on this, parents are sometimes inclined to disinherit the child with a disability, leaving everything to the non-disabled children with verbal instructions to use part of the inheritance for the benefit of the sibling with a disability. This is what is sometimes referred to a gift of moral obligation, and can be equally disastrous. For example, the non-disabled child may not use the inheritance on their sibling's behalf, and is under no legal obligation to do so. Likewise, the spouse of the non-disabled child may want to use the assets for other purposes not related to the sibling with a disability. Even if the non-disabled sibling uses the assets exactly as the parents intended, those assets can be claimed by his or her creditors, can have negative tax consequences on the non-disabled sibling, and can be subject to equitable distribution in the event of divorce.

Most parents want to leave assets to their children when they die. However, if a person with a disability receives assets, the results can be disastrous.

Therefore, lawyers and other professionals familiar with these issues usually recommend the establishment of a special needs trust ('SNT') which will protect the assets, yet make them available to protect and enrich the life of the person with a disability without jeopardizing benefits available from the government. A SNT is a unique legal document that contains a set of instructions describing how assets placed into trust will be administered on behalf of a person with a disability.

Parents and other family members can use a SNT to hold assets for a disabled person. So long as the assets have never vested in the person with a disability, the SNT need not contain a provision reimbursing Medicaid and other providers.

A trust can be established in a Will or as a separate document that is sometimes called a 'living trust.' Usually, it is a mistake to establish the trust in a Will when the chief beneficiary is a person with a disability. When the trust is funded, usually on the death of both parents, the trustee's responsibilities begin.

In an overwhelming number of cases, the child without a disability will serve as trustee of the SNT. It is important, therefore, to understand the role of the trustee. The person, persons, or organization that manage the trust are called the trustees. There can be one or more trustees.

Here are some examples of a trustee's duties starting at this point:

Suppose at the death of the second parent the trust is funded with \$200,000. Let's also suppose that the name of this trust is the 'XYZ Trust.' The trustee's first job is to obtain a tax identification number from the IRS for this trust. This is like a social security number. Next, the trustee must decide where to invest the assets. The trustee may decide to put \$50,000 in a money market account, \$50,000 in Treasury Bills and \$100,000 in a mutual fund. Each account will be opened in the name of the XYZ Trust. If the income is high enough, each year, the trustee will file a tax return for the

trust and pay any taxes owing. The trustee will also draw a fee and obtain reimbursement for expenses.

The trustee must review the beneficiary's needs periodically. For example, suppose Beth lives in a group home and receives social security. The social security benefit must be used before trust as-

*The trustee must review
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periodically.*

sets are touched. Perhaps the group home is sponsoring a trip to Disney World for the residents. The trustee will review this with Beth and her guardian; and, if they agree, the trustee will write a check to cover the cost of the trip. The trustee can also use the trust assets to purchase other items for Beth not provided for by government benefits programs such as televisions, stereos, walkmans, and similar personal items. The trustee, particularly when the trustee is a sibling, can also use the trust assets to pay for time and travel expenses associated with visiting Beth in order to make sure that she is being well cared for. If time and distance does not permit this to happen, then the trustee can pay to have someone else visit Beth, observe her program, and report back to the

trustee, guardian, and other family members.

At Beth's death, the trustee would pay funeral expenses, and then distribute the funds remaining in trust according to the instructions contained in the trust document. The funds might go to other family members, to friends, or to charity.

Sometimes assets belonging to the person with a disability, such as the proceeds of a personal injury case, or even an inheritance given directly to the person, can be sheltered in a SNT. However, this requires court approval and the SNT must conform to the requirements of federal law. The trust must also provide for repayment to Medicaid, and presumably to other government agencies, upon the death of the person with a disability.

SOCIAL SECURITY AND SUPPLEMENTAL SECURITY INCOME

Supplemental Security Income ('SSI') is available to people whose disabilities prevent gainful employment, provided countable resources for an individual are under \$2,000 and monthly income is less than approximately \$500. Parental income and resources are deemed available for children under eighteen living with their parents. People who qualify for SSI automatically receive Medicaid. Because the income and resources of parents are counted until the child turns 18, many people with disabilities fail to qualify for SSI until then. Income and resources of a sibling are never deemed to the sibling with disabilities, regardless of their age or where they live.

SSI pays a maximum of approximately \$600 a month. The actual amount depends upon a number of factors, such as where the person lives and what other income they may have.

Social Security benefits are available to disabled dependents of a parent who collects Social Security benefits or who dies. Individuals who receive Social Security also receive Medicare. Social Security benefits count as income for SSI purposes, and can reduce or eliminate SSI benefits.

A final program is **Social Security Disability Insurance (SSDI)** which pays

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benefits to covered workers who are unable to work because of a disability. After two years, the worker qualifies for Medicare. Typically, SSDI is given to workers who sustain injuries; however, sometimes, people with life-long disabilities qualify because of a work history and experience a subsequent problem with continued employment.

It is important for siblings to understand that most people with disabilities who are unable to work are usually entitled to some type of cash benefit from the social security administration. In cases where the sibling with a disability cannot handle their own finances, the

Social Security Administration will appoint a Representative Payee to handle the benefit. If a parent is not able to serve, then the sibling should take on this role. It is almost always preferred that a family member or close family friend, rather than an agency, such as DDD, become representative payee.

CONCLUSION

There are a number of legal hats that a sibling of an individual with disabilities may wear. With adequate planning, information and supports, siblings can feel confident taking on these responsibilities. Parents must plan carefully before it is too late so that the transfer of authority and responsibility is not disruptive to the sibling with disabilities and is not overly burdensome on the siblings without disabilities. Siblings need to remember they are not alone and that many support groups and experienced professionals are available to help. This guide can be used as a reference to assist the non-disabled sibling with identifying issues, dealing with government agencies, and knowing when assistance from others is needed.

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