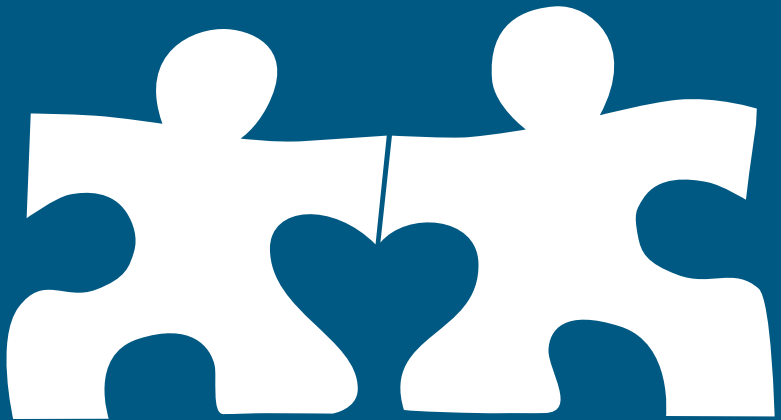


Legal Considerations in Planning for
Individuals with Autism Spectrum Disorders

A Guide for Siblings and Other Caregivers



by Ira M. Fingles, Esq.
Hillary D. Freeman, Esq.
S. Paul Prior, Esq.

Foreword by Ellen Schisler



New Jersey Center for Outreach and Services
for the Autism Community



The New Jersey Center for Outreach and Services
for the Autism Community (COSAC)

1450 Parkside Ave., Suite 22
Ewing, NJ 08638
1-800-4-AUTISM
www.njcosac.org

A Message from Linda S. Meyer, Ed.D., MPA COSAC's Executive Director

Dear Siblings and Caregivers:

Congratulations on locating a document which can truly improve the quality of your lives and the lives of individuals with autism spectrum disorders (ASDs). COSAC recognizes the unique challenges of supporting an individual with an ASD. One of COSAC's major activities is to provide information leading to effective advocacy.

COSAC is dedicated to ensuring that all people with autism spectrum disorders receive appropriate, effective services throughout their lifespans. COSAC is NJ's autism resource for individuals with ASDs as well as the parents and professionals who support them.

COSAC offers the following services to the autism community:

- Information via a toll-free helpline, 1-800-4-AUTISM (1-800-428-8476)
- Educational workshops for parents and extended family members
- Parent support groups and sibling support
- Seminars, workshops, and trainings for professionals
- Assistance with advocacy and legal rights issues
- Promotion of autism awareness to the general public
- Dissemination of current information about autism-related topics and events
- Sponsoring the largest NJ Conference
- Legislative activity promoting public policy and systems advocacy changes
- Short-term emergency care

Visit COSAC's website: www.njcosac.org to:

- Become an action advocate
- Receive the latest information regarding autism spectrum disorders and advocacy activities.

COSAC maintains a comprehensive list of resources which can provide you with additional information regarding the topics outlined in this booklet. For a copy of this list, please call COSAC at 1-800-4-AUTISM or visit their website at www.njcosac.org

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Foreword

About a year and a half ago, my sister and I sat down with my parents to hold the first ever meeting of the “Board of Directors” of Jeffrey, Inc. Jeffrey is my older brother. He’s in his mid 40s and was diagnosed with a developmental disability four decades ago. He lives in a group home not too far from my parents’ home.

My sister and I requested a formal meeting to review all the elements that surround my brother’s care. We’ve been in “management training” since we were kids. As time has passed, through observation, investigation, and detailed instruction, we’ve learned how this metaphoric corporation works.

During that meeting, I was obsessed with finding out the name of the catalog from which my dad orders my brother’s extra wide shoes. It was a little, inconsequential detail that for me seemed much easier to latch onto than the far more somber issues. Yes, someday my sister and I would become “Chairwoman” and “CEO.”

It’s not a conversation you want to have, but it’s a conversation siblings and their parents must have. I’ve heard many parents express their anguish wondering “who will take care of my son/ daughter when I die?” I’ve heard my own parents, in a clear effort to avoid burdening us, offer us an opportunity to “resign from the corporation.” We’ve decided, however, that we are employees for life.

These decisions are not easy. Every situation is unique. Family dynamics vary greatly. Whatever ultimate choices are made in your family’s “corporation,” it is essential that you are prepared. I strongly encourage you to use this guide as a tool and a conversation starter. Armed with information and assistance from experts like Hinkle, Fingles & Prior, and organizations like COSAC, these difficult decisions can be made a little easier.

Ellen Schisler,
Director of Development, COSAC

“Who will care for my brother or sister when my parents are gone?”

INTRODUCTION

In the past, available information for families of individuals with autism spectrum disorders (ASD) has focused on issues of importance to parents as caregivers. This information has been critical, but this approach has failed to recognize the primary role that siblings and other extended family members often play in the lives of adults with ASD, particularly as parents age.

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

Extended family members may feel removed or uninformed, and intimidated by their lack of understanding of the

day-to-day needs of the family member with ASD.

As time passes, adolescent and adult siblings may be concerned that they will have to financially support their brother or sister. They may wonder whether their sibling will need to live with them in their home, or whether increased caregiving demands might interfere with their own goals and dreams.

Uncertainty about how their sibling's needs will be met after the parents are no longer able to provide care is perhaps the most anxiety-provoking issue to non-disabled family members.

These concerns are natural and are best addressed openly and directly. Parents should take an active role in ensuring that all of their children, both disabled and non-disabled, manage these issues and can go on with their lives in a comfortable, secure manner after they themselves are gone.

These are the types of issues siblings and other family members 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 ASD and a summary of actions that parents, adult siblings and other caregivers can take to plan for the future and ensure services are continued without interruption.



CHECK POINT

The following questions are critical to maintaining effective care for individuals with ASD:

- Who will make decisions on behalf of my child with ASD 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 he/she reaches adulthood?
- What services are available to make sure that my child 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 met?
- 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 without jeopardizing his or her vital services and benefits?
- How do I provide funds for the benefit of my child without subjecting those funds to claims by the government for repayment for services that my child receives?

Issues affecting individuals with
ASD fall into four broad
categories:

1
special
education services
for children
under the age of
twenty-one

2
adult services
for those over
the age of
twenty-one

3
guardianship and
estate planning
considerations

4
income and
medical
benefits


SPECIAL EDUCATION

It is unlikely that siblings or other family members of individuals with ASD will be directly involved in the educational needs of their brother or sister. Nevertheless, siblings and other decision-makers should have a basic understanding of special education rights and obligations.

Children between the ages of 3 and 21 with disabilities that negatively affect learning are entitled to special education services at no cost to families. These services are federally mandated 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 for identifying, evaluating and then classifying children with disabilities as eligible for special education and related services. State regulations stipulate timelines and the methods to accomplish this, and administrative procedures to resolve disputes.

Federal law requires that each child must receive a program that meets his or her unique and individual needs. Every year, school districts must develop a written Individualized Education Program (IEP) that includes measurable goals and that details the services to be provided. For some children, the IEP might involve classroom modification, or individual instruction or therapy. Other children might require placement in a special class



CHECK POINT

- Do you have your brother or sister's most recent IEP?
- Were transition services provided as stated?
- Do you have school records, including evaluations and assessments?

or a private school which specializes in serving children with ASD. Private schools can provide services on a day or a residential basis. Depending on need, children with ASD might be entitled to educational services during the summer months.

Schools must document a child's progress.

School evaluations and other records can be helpful later in life to determine eligibility for adult services and other government assistance programs. Parents and guardians should keep records provided by the school at least until adult services and social security benefits (discussed later in this guide) are secured. Keeping these documents will help in the caregiver's efforts on behalf of the adult with ASD.

ADULT SERVICES

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

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

Day Services

Individuals with ASD should be provided 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.

There are waiting lists 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 as part of the transition process.



CHECK POINT

- Is your brother or sister eligible for DDD services?
- Is he / she on a waiting list? If so, for what service?
- Who is your DDD casemanager?

Ideally, these services should be in place by graduation. If this is not possible, then it is critical that these services are in place before parents are no longer able to provide care.

If parents have not done so before they are gone, siblings or other caregivers must immediately acquire these services for their brother or sister. In some cases, an adult with ASD may be entitled to an emergency day placement.

Residential Services

DDD is the primary source of residential services and supports for individuals with ASD 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 programs, in which an individual lives on his or her own and receives training and periodic visits from support staff. It also is possible to secure funding for services to allow an individual to remain in his or her family's home with supports and services through DDD's *Real Life Choices* program.

Securing the appropriate placement takes time. Waiting lists for residential services in New Jersey can run seven years, or longer. In order to receive a residential placement, 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 available options when residential placement is made and help avoid a crisis.

Some parents may believe that the sibling without a disability will allow their brother or sister with ASD to live with them after they (the parents) die.

Parents should be mindful of the needs of *both* the child with and without the disability and understand that this often is not a realistic expectation.

Children without disabilities and other family members often have families and work responsibilities of their own that make providing care to an adult with ASD difficult, if not 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.

Siblings owe it to themselves, their parents, and their brother or sister to be candid about their willingness and ability to provide lifelong care to their adult sibling with ASD.

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

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Many state agencies are entitled by law to seek reimbursement for the costs of services. Currently, the only service in New Jersey 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, and not the parents or legal guardians.

For this reason, it is important to ensure that the assets of the person with ASD are correctly sheltered to limit exposure and help avoid the need to pay for services that otherwise would be provided free by the government. This is discussed in more detail on page 14.

Siblings owe it to themselves, their parents and their brother or sister to be candid about their willingness and ability to provide lifelong care to an adult with a disability.



CHECK POINT

- Have you discussed your sibling's long-term needs with your parents?
- What are your parents' hopes or expectations for your role in your sibling's life as they age?
- Are you able and willing to be a decision-maker for your sibling with disabilities?
- Do you have concerns or reservations about the role your parents want you to assume?
- Do you have the support YOU need to take on the responsibilities your parents now have?
- What individuals or agencies can help you?

GUARDIANSHIP

No single issue will impact non-disabled family members more than guardianship. After parents are gone, a brother or sister of a person with ASD is usually the person best suited for this role. Therefore, it is important for the sibling to have a basic idea of a guardian's responsibilities.

In New Jersey, the age of majority is eighteen. In the eyes of the law, whether someone has ASD or not, he or she is legally permitted to make his or her own decisions at the age of eighteen. However, if an individual's disability precludes him or her from making important decisions independently, it may be 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 on his/her own. A guardian also can 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. A guardian of the property does not have power over any assets held in trust unless the guardian also is the trustee. (See page 13 for more on the role of a trustee.)



CHECK POINT

- Have your parents secured guardianship?
- Are you willing and able to serve as guardian for your sibling with disabilities when your parents are no longer able?
- Do your parents' wills identify a successor guardian?

In order to have guardianship, a court must first find that the person with ASD 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. Once they have secured guardianship, parents also can appoint a successor guardian in their will. The court also may appoint a brother, sister or other relative to serve as guardian with the parents, or alone after the parents have died. Guardianship can be temporarily delegated to others through a power of attorney.

Guardians are obligated to make sure that the person with ASD is safe and that decisions are made in his or her best interest. The guardian does not bear any risk for the person's acts or debts, and is not under a legal obligation to provide direct care to the person. Therefore, there is no downside to serving as someone's guardian.

Parents and family members should understand that the non-disabled family member may one day serve as their relative's guardian. Parents should discuss this issue long before the need arises, and help the non-disabled family members 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, 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 has co-payments and deductibles. It does not have an income or resource test.

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

Eligibility for Medicaid is similar to that of Supplemental Security Income (SSI). The applicant must have a monthly in-

come of approximately \$600 or less and no more than \$2,000 in countable assets. Also, like SSI, income and resources of parents are counted only if the potential recipient is under age eighteen.

Medicaid has the authority to waive 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, and is administered by the New Jersey Division of Developmental Disabilities.

For more on SSI and SSDI, see page 15.



CHECK POINT

- Is your sibling eligible for Medicare and / or Medicaid?

ESTATE PLANNING CONSIDERATIONS

Most parents want to leave assets to their children when they die. But if a person with ASD who is receiving public assistance receives additional assets, the result can be tragic. The receipt of such assets will jeopardize Medicaid and SSI, and the assets also may be subject to recoupment by Medicaid, or by the State of New Jersey if the person is receiving residential services.

Because of these rules, parents sometimes are inclined to disinherit the child with ASD, leaving everything to their non-disabled children with verbal instructions to use part of the inheritance for the benefit of the sibling with a disability. Sometimes referred to as ‘gifts of moral obligation,’ this course 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 ASD. Even if the non-disabled sibling uses the assets exactly as the parents intended, those assets can be claimed by his or her creditors, have negative tax consequences on the non-

disabled sibling, and be subject to equitable distribution in the event of divorce.

Therefore, legal professionals usually recommend the establishment of a special needs trust (SNT), or ‘trust with limitation.’ A SNT 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 such a trust to hold assets for an individual with ASD. So long as the assets have never vested in the person with ASD, the trust need not contain a provision reimbursing Medicaid and other providers.

A trust can be established in a parent’s 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 ASD. When the trust is fund-

Most parents want to leave assets to their children, but if a person with a disability receives even modest assets, the results can be disastrous.


ed, usually on the death of both parents, the trustee's responsibilities begin.

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

Here are some examples of a trustee's duties:

Suppose, at the death of the second parent, the SNT 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. The trustee also will draw a fee and obtain reimbursement for expenses.

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



CHECK POINT

- Is there a special needs trust in place for your disabled sibling?
Who is the trustee?
- Do all family members know about the trust, and know not to leave assets directly to your disabled sibling?
- Has the trust instrument been carefully reviewed to ensure that assets will not affect eligibility for services that would otherwise be free?

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; if they agree, the trustee will write a check to cover the cost of the trip. The trustee also can use the trust assets to purchase personal items for Beth, such as a television, stereo or i-Pod, that are not provided for by government benefits programs. The trustee, particularly when the trustee is a sibling, also can 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 do not permit this to

happen, the trustee can pay someone else to visit Beth, observe her program and report back to the trustee, guardian and other family members.

At Beth's death, the trustee would use trust assets to 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, friends, or charity.

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 also must provide for repayment to Medicaid, and presumably to other government agencies, upon the death of the person with a disability.

Letters of Intent are devices used to pass on key information from parents to another caregiver or successor guardian. They list factual information such as educational history, medical history and location of vital records, as well as information about parental aspirations for the person with a disability, including goals for work and living arrangements. A prototype for a letter of intent can be downloaded at www.hinkle1.com.

ELDER LAW CONSIDERATIONS

Even the best plans can be upset if one or both parents need to enter a nursing home. Consideration should be given to the following:

Long-Term Care Insurance (LTCI) to pay for nursing home services can be expensive, but in many cases, it is worthwhile. Medicaid and standard medical insurance do not cover extended stays in nursing facilities. LTCI also guarantees the ability to choose the best nursing facility.

A Durable Power of Attorney is useful to allow the transfer of assets in the event a parent becomes incapacitated or gravely ill. Not everyone is comfortable with this, but it should be discussed, not only for the benefit of the parents themselves, but also for the adult child with ASD.

Finally, consideration should be given to a unique provision in the federal Medicaid law, which allows a parent to transfer funds to a disabled child and still qualify for Medicaid. Care must be taken with such a transfer, however, to insure that Medicaid benefits for the child with disabilities are not lost. A special needs trust often is required.

The authors urge that families planning for the future of a child with ASD not overlook these vital issues.

SOCIAL SECURITY & SUPPLEMENTAL SECURITY INCOME

Supplemental Security Income (SSI) is available to people whose disabilities prevent gainful employment, provided countable resources are under \$2,000 and monthly income is less than approximately \$800 - \$900. 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 a sibling with disabilities, regardless of his or her age or where he or she lives.

SSI pays benefits of approximately \$475-\$675 a month. The actual amount depends upon a number of factors, such as where the person lives and what other income he or she may have.

Social Security benefits are available to disabled dependents of a parent who collects Social Security benefits or dies. Individuals who receive Social Security also receive Medicare. Social Security



CHECK POINT

- Is your disabled sibling eligible for SSI or SSDI?
- Who is the representative payee?

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 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. Sometimes, however, people with life-long disabilities qualify because of a work history and experience a subsequent problem with continued employment.

When considering eligibility for SSI or SSDI, the income and resources of a sibling are never deemed to a sibling with disabilities, regardless of his or her age or where he or she lives.

It is important for siblings to understand that most people with ASD who are unable to work usually are entitled to some cash benefit from the Social Security Administration. In cases where the sibling with ASD cannot handle his or her own finances, the Social Security Administration will appoint a

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

CONCLUSION

There are a number of legal hats that siblings and other family members of an individual with ASD may wear. With adequate planning, information and supports, siblings can feel confident taking on these responsibilities. Parents must carefully plan before it is too late so that the transfer of authority and responsibility is not disruptive to the child with ASD and not overly burdensome to family members without disabilities. All caregivers need to remember they are not alone and that many support groups, experienced professionals and agencies such as COSAC are available to help.

Parents must carefully plan before it is too late so that the transfer of authority and responsibility is not disruptive to the child with ASD and not overly burdensome on family members without disabilities.

Hinkle, Fingles & Prior, Attorneys at Law

The firm maintains a multi-state law practice in New Jersey and Pennsylvania with offices in Lawrenceville, Marlton, and Florham Park, New Jersey, and in Bala Cynwyd and Plymouth Meeting, Pennsylvania.

They lecture and write frequently on topics of law, aging, disability, special education, health care and estate planning. They are available to speak to groups in New Jersey and Pennsylvania at no charge.

About the Authors

Ira M. Fingles has provided legal representation to individuals with disabilities in a variety of areas, including special education, adult services and estate planning for over fifteen years. His motivation to enter the field stems from his experiences with his sister, who has multiple disabilities. He is a trustee of the The Greater Philadelphia Chapter of the Autism Society of America and volunteers his services to several disability organizations. He holds a JD from Temple University School of Law and is a member of the New Jersey, Florida and Pennsylvania Bars.

Hillary D. Freeman is deeply committed to her work representing people with disabilities and their families. As the sister of a man with ASD, she is able to combine personal experience with her legal training to help families advocate for services and supports. She has experience before Administrative agencies and Superior Court in special education issues, Section 504, and guardianship and adult services. She is a member of the American Association for Trial Attorneys, the International Dyslexia Association, and COSAC. She holds a JD from Widener University School of Law and is licensed to practice in both Pennsylvania and New Jersey.

S. Paul Prior has spent his legal career representing people with disabilities. As the brother of an individual with ASD, he has a lifelong commitment to disability law. He has successfully argued leading cases before the New Jersey Supreme Court, Third Circuit Court of Appeals, as well as other state and federal courts. He holds a JD from Seton Hall University School of Law, and serves on the board of directors of the Arc of New Jersey, Special Olympics New Jersey and the Eden Institute Foundation. He holds a JD from Seton Hall University School of Law, and is a member of the Elder Law Section of the New Jersey State Bar Association.

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Hinkle, Fingles & Prior
Attorneys at Law

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www.hinkle1.com

Lawrenceville · Marlton · Florham Park, NJ
(609) 896-4200

Bala Cynwyd · Plymouth Meeting, PA
(215) 860-2100