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Legal Considerations in Planning for Individuals with Autism Spectrum Disorders: *A Guide for Siblings and Other Caregivers in Pennsylvania*

by Ira M. Fingles, Esq. & S. Paul Prior, Esq.

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Introduction

In the past, available information for families of individuals with autism 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 autism, particularly as parents age.

Siblings of individuals with autism face unique challenges from the earliest stages of their lives. Young children maybe frightened or bewildered by their sibling's disabilities. They can be resentful of the increased parental attention that the sibling with autism 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 autism.

As time passes, adolescent and adult siblings may be concerned that they will have to financially support their brother or sister with autism. 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.

While this guide makes reference to individuals with autism, it applies equally to all individuals with autism spectrum disorders, including pervasive developmental disorder - not otherwise specified (PPD-NOS), Aspergers Syndrome, and the other conditions falling on the autism spectrum.

Issues affecting individuals with autism 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

Checkpoint

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

- Who will make decisions on behalf of my family member with autism after my parents gone?
- What needs to be done to ensure that a decision-maker is legally empowered to act on behalf of my family member with autism after he/she reaches adulthood?
- What services are available to make sure that my family member with autism is provided an appropriate job or day program?
- How can I ensure my family member with autism has a place to live that can meet his or her needs in a safe environment?
- How can I make sure my family member'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 family member with autism without jeopardizing his or her vital services and benefits?
- How do I provide funds for the benefit of my family member with autism without subjecting those funds to claims by the government for repayment for services?

Special Education

It is unlikely that siblings or other family members of individuals with autism 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 with disabilities up to the age of 21 are entitled to special education services at no cost to families. These services are federally mandated in all states. Special education in Pennsylvania is the responsibility of a variety of agencies depending upon the student's age. Generally, services for children ages 0 to 2 are provided by local Mental Health/Mental Retardation ("MH/MR") agencies. Children ages 3 to 5 are usually served by county-based Intermediate Units or other agencies under contract with the Pennsylvania Department of Education. Once a child reaches school age, the student's local school district becomes primarily responsible for providing services.

School districts and other responsible agencies are responsible for locating, evaluating and then identifying all 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 modifications, or individual instruction or therapy. Other children might require placement in a special class or a private school which specializes in serving children with autism. Private schools can provide services on a day or a residential basis. Depending on need, children with autism might be entitled to educational services during the summer months ("Extended School Year" services). They may also require services that go beyond the regular school day ("Extended School Day" services).

The special education system places a great emphasis on the active participation of parents and other caregivers in the process of deciding how the student's needs will be met. Elaborate procedures are required to ensure that parents are afforded full status as an "equal member" of the team responsible for making decisions. If a parent is not available to fulfill this role, siblings or other family members may take their place.

Substantively, school districts are obligated to provide students with disabilities with a "Free Appropriate Public Education" or "FAPE." Whether this has been done is determined primarily by whether the student is making significant progress in the areas of need created by their disabilities. For a child with autism, this would focus not only upon academic progress but also progress in non-academic areas such as behavioral control, social skills, vocational skills, and independent living skills. It is the responsibility of the school district to document whether and how much progress the student is making.

School evaluations and other records can be very helpful later in life to establish eligibility for adult services and other government assistance programs and to help secure appropriate services. Parents and other caregivers 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 autism.

CHECKPOINT

- Do you have your brother or sister's most recent IEP?
- Is an appropriate transition plan in place?
- Do you have school records, including evaluations and assessments?

Adult Services

Unlike special education, services for adults with autism are not federally mandated and are not always free. As a result, many families experience a great deal of stress and anxiety when an adult child with autism leaves the comparatively protected confines of the educational system to enter the confusing, and sometimes overwhelming, world of adult services. Nonetheless, with proper planning, it is possible to secure appropriate services to ensure that the individual's needs are fully met.

As of this writing, the service delivery system for individuals with autism spectrum disorders living in Pennsylvania is in a state of transition. Many changes have been implemented in the structure of the State agencies that serve individuals with autism, and even greater changes are on the horizon. It is expected that many of these changes will result in significant improvements in the availability and quality of services for adults with autism spectrum disorders.

Currently, services for adults on the autism spectrum are provided primarily through the county-based Mental Health/Mental Retardation ("MH/MR") system. Funding, and hence services, are extremely limited in the Mental Health system. Consequently, many families seek to secure services through the Mental Retardation system. Funding is provided through "Medicaid Waivers" (discussed on page 5).

In order to be considered Mentally Retarded, an individual must demonstrate below-average cognitive functioning along with impairments in adaptive functioning; i.e., communication, self-care, home living, social skills, functional academics, leisure, and work. Contrary to what most people believe, it is not necessary that an individual's IQ must be below 70 to qualify for Mental Retardation services. Individuals with higher IQ's who demonstrate severe limitations in adaptive functioning (such as behavior, self-care skills, communication skills, and the like) may still be able to receive Mental Retardation services.

There are a number of services that are provided through the Mental Retardation system, some of which can be critical to the well-being of the individual on the autism spectrum. Among the most important are day services and residential placement.

Day Services

Individuals with autism spectrum disorders should be provided with constructive, structured activities during the day. These services are available through the Mental Retardation system, or in some cases, the Office of Vocational Rehabilitation Services ("OVR"). Depending upon one's preferences and ability levels, these services can range from placement in workshop settings with other individuals who have severe disabilities, to the provision of job coaching and other supportive services in a community-based competitive employment setting.

There are waiting lists for some services, so it is important to apply early. It is strongly recommended that family members and other caregivers begin the process of advocating for day services at least five years before the individual is expected to graduate from the special education system. This should be done in writing to the local Mental Health/Mental Retardation agency on at least an annual basis. These letters should contain a reminder of the individual's expected graduation date and a request that all necessary steps be taken to ensure that an appropriate day program is available immediately upon graduation. The Mental Health/Mental Retardation agency is then obligated to place the individual in the appropriate waiting category through the PUNS system (discussed on page 5).

It is a tragedy, and a highly avoidable one at that, to allow a sibling with autism to languish without constructive activity after he or she graduates from the educational system. Hard-won skills that may have taken years to acquire can be lost in a matter of weeks or

months, and problematic behaviors may emerge which can be extremely difficult to extinguish. If parents have not done so already, siblings or other caregivers must immediately acquire day services for their adult brothers or sisters who have left the educational system. In some cases, an adult with autism may be entitled to an immediate day placement on an emergency basis.

Residential Services

The Mental Retardation system is the primary source of residential services and supports for individuals on the autism spectrum in Pennsylvania. Placement options range from group homes, in which several individuals with disabilities live together and receive around-the-clock care, to supervised apartments and supported living programs in which an individual lives on his or her own and receives training and periodic visits from support staff. It may also be possible to secure services to allow an individual to remain in his or her family's home with supports and services.

Securing the appropriate placement takes time. Waiting lists for residential services in Pennsylvania can run many years (see the discussion of the "PUNS" system on page 5 for more about waiting lists). Suffice it to say that it is important for siblings to encourage parents to seek assignment to the top category of the waiting list while they are still healthy. Doing so will increase the number of available options when a residential placement is made, and will help avoid a crisis.

Some families believe that the best arrangement is to allow the sibling with autism to live with his or her non-disabled sibling after the siblings' parents die. This may not always be the most preferable arrangement, both for the sibling with autism and his or her non-disabled sibling. With all the best intentions, it may still be impossible for the non-disabled sibling to provide the necessary level of care and support to the sibling with autism as a result of the non-disabled sibling's obligations to his or her own children and other family members, work responsibilities, and other personal demands. Likewise, the sibling with autism may be better served by living in an environment in which professional, specialized services are provided and in which the individual's abilities to live independently can be maximized.

Non-disabled siblings owe it to themselves, their parents, and most importantly, to their brother or sister with autism to be candid about their willingness and ability to provide lifelong care to their adult sibling with autism.

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

- CHECKPOINT**
- Is your brother or sister eligible for MH/MR services?**
- Is he/she on a waiting list? If so, for what service?**
- Who is your MH/MR Supports Coordinator?**

Medical Assistance (Medicaid)

Medicaid is a federal health insurance program that provides medical coverage for people with disabilities who have low income and assets. In Pennsylvania, Medicaid is called “Medical Assistance” or “MA.”

Medical Assistance covers all medical expenses. It will also pay for all medically necessary equipment, which may include things like augmentative communication devices. There are no deductibles or co-payments under the Medical Assistance program, though not all physicians will accept it.

Eligibility for Medical Assistance is similar to that of Supplemental Security Income (SSI). The applicant must have a monthly income of approximately \$850 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. However, children under the age of 18 may be eligible for Medical Assistance through the so-called “Loophole,” which disregards family income and resources.

Medicaid Waivers

Under the federal Medicaid program, states are allowed to vary the eligibility requirements and services available to individuals with disabilities if doing so will allow the state to prevent such individuals from being institutionalized. These programs are called “Medicaid Waivers.”

In Pennsylvania, Medicaid Waivers are a very important source of funding for individuals with autism. The two waiver programs which are most important are the Person and Family Directed Services (“P/FDS”) Waiver and the “Consolidated Waiver.” Both waivers provide things like day programs, job coaching, transportation, and specialized therapies. The main differences are that under the P/FDS Waiver, services are capped at approximately \$21,000 per year, and residential services are not available. There is no specific cost cap under the Consolidated Waiver, and residential services are available.

The “PUNS” System

Each year, Pennsylvania only provides funding for a limited number of “slots” under both the P/FDS and Consolidated Waivers. Consequently, there are waiting lists for services under both waivers. The waiting lists are managed through the PUNS system. PUNS stands for “Prioritization of Urgency of Need for Services.” A PUNS assessment must be completed at least once each year. During the assessment, the individual’s Supports Coordinator will ask a series of questions to determine the urgency of the individual’s need for services. Based upon the information provided, a person is placed into one of three PUNS categories:

- Emergency, which indicates a need for services immediately or within the next six months.
- Critical, which means services will be needed within the next 2 years.
- Planning, which means that services are not needed for more than two years

It is important to ensure that the correct PUNS category is selected. It is virtually impossible to secure services unless the individual is in the “emergency” category, although in some counties, a small number of people may be placed off of the “critical” list each year. If you believe that your sibling has not been assigned to the proper PUNS category, you should contact your Supports Coordinator to request an appeal of that decision.

Reimbursement for Services

If an individual receives services through the MH/MR system, as well as certain other governmental agencies, the government may have a right to charge the individual for the costs of the services that are provided to the extent that the individual has the resources to pay for them. For this reason, it is important to ensure that the assets of the person with autism 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 8.

Medicare

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.



CHECKPOINT

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

Supplemental Security Income and Social Security Disability Insurance

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 \$850. 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, whether the sibling with autism lives with him or her, or whether the non-disabled sibling has been appointed as guardian of the individual with autism.

SSI pays benefits of approximately \$450- \$650 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.

Individuals with autism may also be eligible for Social Security Disability Insurance (SSDI) benefits. This program provides benefits to individuals who have worked and paid Social Security taxes for a sufficient period of time who then become disabled. It also pays benefits to disabled dependents of a parent who collects Social Security benefits or dies, so long as the individual became disabled before they reached the age of 22. This is the more common manner in which individuals with autism spectrum disorders qualify for SSDI benefits. Individuals who receive SSDI also receive Medicare. SSDI benefits count as income for SSI purposes, and can reduce or eliminate SSI benefits.

It is important for siblings to understand that most people with autism who are unable to work usually are entitled to some cash benefit from the Social Security Administration. In cases where the sibling with autism 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.



CHECKPOINT

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

Guardianship

Guardianship is one of the most important issues that must be dealt with by non-disabled family members. After parents are gone, a brother or sister of a person with autism 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 Pennsylvania, the age of majority is eighteen. In the eyes of the law, whether someone has autism 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 or 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 8 for more on the role of a trustee.)

In order to have guardianship, a court must first find that the person with autism 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 can appoint a successor guardian in their wills. 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.

Guardians are obligated to make sure that the person with autism 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.

CHECKPOINT

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

Estate Planning Considerations

Most parents want to leave assets to their children when they die. But if a person with autism who is receiving public assistance receives additional assets, the result can be tragic. The receipt of such assets will jeopardize Medical Assistance and SSI, and the assets may also be subject to recoupment by state or county agencies that provide services to the person.

Because of this, parents are sometimes inclined to disinherit the child with autism, 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 autism. 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) (sometimes also called a “Supplemental Needs Trust”). 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 autism. So long as the assets have never vested in the person with autism, the trust need not contain a provision reimbursing the Department of Public Welfare and other service 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 autism. When the trust is funded, 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 trustee. 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 may also 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 Disability Insurance (SSDI) benefits. The SSDI benefits must be used before trust assets 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 iPod, 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. Typically, the funds 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 the Department of Public Welfare, and possibly 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 protocol for a letter of intent can be downloaded at www.hinkle1.com.

CHECKPOINT

- 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?

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 pays for nursing home services and sometimes home care. Such insurance can be expensive, but in many cases, it is highly worthwhile. Medical Assistance and standard medical insurance do not cover extended stays in nursing facilities. Long Term Care Insurance 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 autism.

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. (Ordinarily, a parent is disqualified from receiving Medicaid benefits for a period of time if funds are given away.) 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 families planning for the future of a child with autism not to overlook these vital issues.

Conclusion

There are a number of legal hats that siblings and other family members of an individual with autism 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 autism 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 the Greater Philadelphia Chapter of the Autism Society of America are available to help.

CHECKPOINT

- 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?**

Authors' Bios

Ira M. Fingles has devoted his legal career to the representation of individuals with disabilities and their families. His motivation to enter this field stemmed from his experiences with his sister, who has multiple disabilities. He has provided legal representation to individuals with disabilities in a variety of areas, including educational rights for children with disabilities, benefits and services for adults with disabilities, guardianship, and estate planning. He has argued precedent-setting cases in federal and state court, and before administrative agencies in Pennsylvania and New Jersey. He has written extensively on topics related to disability law and has presented to disability groups across the nation. Ira is Immediate Past President of the Autism Society of America - Greater Philadelphia Chapter, and serves on the board of directors and as an advisor to disability advocacy groups in Pennsylvania and New Jersey. He received his JD from Temple University School of Law and is a member of the Pennsylvania and New Jersey Bars.

S. Paul Prior has spent his legal career representing people with disabilities. As the younger brother of a man with autism, he has a life-long commitment to disability law. His legal work has focused on special education, guardianship, financial entitlements, and access to appropriate services. A substantial part of his practice is devoted to assisting families in estate and trust matters. 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 served as a federal monitor overseeing conditions at state-operated institutions. He holds a JD from Seton Hall University School of Law, and serves on the board of directors of for the Arc of New Jersey, Special Olympics New Jersey and the Eden Foundation. He is a member of the Elder Law Section of the New Jersey Bar Association. He writes and lectures frequently on topics concerning the law and disability as well as issues affecting siblings.

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**Bala Cynwyd, PA • Plymouth Meeting, PA
Lawrenceville, NJ • Marlton, NJ • Florham Park, NJ**

(215) 860-2100

(609) 896-4200 • (973) 660-9060

About Hinkle, Fingles & Prior, Attorneys at Law

Attorneys from the firm 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.