A Lifetime of Advocacy:
What Individuals and Families Living with Turner Syndrome Need to Know

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I. Introduction

This booklet has been created to provide families with children and individuals living with Turner Syndrome and other special needs with a lifetime guide on how and when to advocate for services over one's lifetime. Many individuals feel uneducated about disability benefits and health insurance systems. As a result, many are either uninformed or misinformed about obtaining benefits for themselves or their family member and appealing adverse determinations regarding the same.

According to the Turner Syndrome Foundation, healthcare for children and women with Turner Syndrome should be guided and monitored by an endocrinologist specializing in Turner Syndrome. One of the biggest hurdles upon diagnosis is organizing a team of physicians knowledgeable about the condition. It is beneficial that an endocrinologist specializing in Turner Syndrome carefully manage continuing care over the lifespan. The **National Institute of Health Clinical Practice Guidelines** outlines specific recommendations for health screenings, treatments, early interventions, and preventative care; this document should be provided to each member of the medical team. It is recommended that the patient family maintain personal records by creating two binders – one for education and one for medical information. This will save time, later, should a need arise to access this information.

Many women and families living with Turner Syndrome have found that developing personal connections within the community, sharing information about the condition with others, partaking in research opportunities, and contributing to the common good to be rewarding and fulfilling. Of course, every individual is unique, and you will follow the path that is right for you.

In the meantime, this booklet will help you as you work to access care through a variety of health care service systems; as well as, other federal and state sources that provide primary or additional coverage.

II. Your Health Care Insurance Coverage

The world of special needs is intricate. The health insurance system is even more complex. It is, therefore, critical that you have a complete understanding of your coverage in order to secure all the services you, your child or adult child needs. The more you know, the more you will maximize coverage and minimize your financial responsibility. Quite frequently, health insurance plans reduce, limit or deny coverage – often claiming the requested service is not medically necessary. When this occurs, it is important to know your appeal rights and exercise them in a timely manner.

Depending on the state in which you reside and what type of health insurance plan provides coverage, parents can continue coverage for adult disabled children. Typically, proof of disability is necessary to extend coverage for a dependent under private health insurance plans. Under Federal law, private insurance plans must cover dependents through their 26th year. In New Jersey, dependents 30 years and younger must be provided dependency coverage under New Jersey insurance mandates where other group health insurance is unavailable. Effectively, New Jersey's dependency coverage extends through the child's 31st year.

A. Types of Coverage

There are several types of insurance coverage:

- Private insurance (individual & group health plans);
- Self-funded/Self-insured plans;
- Public assistance (Medicaid and Medicare); and
- The State Health Benefits Program.

Because the coverage and appeal rights differ based on the type of plan and by state, it is important to read your member handbook to determine what type of coverage you have and to what appeal rights you are entitled.

1. Private Insurance

Private insurance is provided by your employer or obtained on your own. Plans are governed by state insurance laws. Services and procedures covered under private plans vary widely, requiring referrals for specialists or use of certain providers, such as labs, in order to receive coverage. Additional costs or co-payments may be required, particularly if you elect to use providers out-of-network. It is important to obtain a copy of your member handbook in order to be informed of the coverage offered and your financial responsibilities.

To learn more about the private insurance plans in your state, contact the New Jersey Department of Banking & Insurance. *See Important Resources.*

2. Self-Funded/Self-Insured Plans

Self-Funded/Self-Insured Plans are health insurance plans offered by a private employer, which differ from typical employer-provided plans in that the employer (not an insurance company) assumes the risk of insuring its employees. As a result of this arrangement, these types of plans have greater latitude as to what they do and do not cover. Typically, these types of plans either eliminate coverage for skilled nursing or significantly limit the number of therapy services. Your Human Resources Department will be able to tell you whether you have this type of plan and provide you with your member handbook outlining what your plan covers.

To learn more about self-funded/self-insured plans, contact the U.S. Department of Labor. *See Important Resources.*

3. Public Assistance Programs

Public Assistance Programs include Medicaid (Fee-for-Service, EPSDT Program, Managed Care, and Waiver Programs) and Medicare coverage.

Medicaid (a.k.a., Medical Assistance) is a federal-state entitlement program for low-income Americans. There are three basic groups of low-income people: parents and children, elderly, and the disabled. To be eligible for Medicaid, one must have limited financial resources (that is, no greater than approximately $668 in monthly income and no more than $2,000 in countable resources).

Each state's Medicaid State Plan provides the following Mandatory Services: in-patient and out-patient hospital treatment, lab tests, x-rays, EPSDT services, home healthcare, physician services, nurse midwife, family assistance, and nursing home for those over the age of 21.

In New Jersey, the following Optional Services are also included in the Medicaid State Plan and are available to its Medicaid beneficiaries: residential treatment centers, optical appliances, dental, optometry, chiropractic, psychology, podiatrist, prosthetics and orthotics, drugs during long-term care, durable medical equipment, hearing aides, hospice, transportation, private duty nursing services, clinic services, therapies (speech, occupational, and physical), intermediate care (ICF/MR), TB-related services for TB infected persons, nursing facilities (21 years of age and older), in-patient psychiatric care for under 21 years of age and older than 65). For information about your state's optional services, visit www.cms.gov.

Among the Mandatory Medicaid services contained in the State Medicaid plan is the **Early and Periodic Screening, Diagnosis and Treatment ("EPSDT") Program**. EPSDT services must be made available to every Medicaid-eligible child under the age of 21. Under EPSDT, the state must provide four types of screening services: medical, vision, dental, and hearing; and is required to provide coverage for medically necessary treatment.

EPSDT covers a wide range of treatment services, including all of the above-listed Medicaid Mandatory and Optional Services when they are medically necessary to "correct or ameliorate defects and physical and mental illnesses and conditions" regardless of whether such services are covered under the state plan. While there is no legal definition of "medical necessity," it is generally defined by health plans as:

- Necessary for the symptoms and diagnosis or treatment of the condition, illness or injury;
- Provided for the diagnosis or the direct care and treatment of the condition, illness or injury;
- In accordance with general accepted medical practice;
- The most appropriate level of medical care needed;
- Accepted by a professional medical society in the United States as beneficial for the control or cure of the illness or injury being treated; and
- Furnished within the framework of generally accepted methods of medical management currently used in the United States.

Covered services under the EPSDT Program include: case management, home health care, personal care, private duty nursing, physical therapy and related services, respiratory care, hospice care, rehabilitation, durable medical equipment, hearing aids, eyeglasses, orthodontic care, and personal care services.

In order to obtain and maintain coverage for services, your treating physician must provide written documentation that the requested service is medically necessary, *as generally defined above*. The agency or individual that provides services should always keep precise notes on your condition and continued need for the particular service. Without this documentation, medically necessary services are frequently reduced or terminated.

Medicaid-funded Home and Community-Based Waiver Programs ("Waivers") provide disabled individuals with care in the home and community as an alternative to institutional care. The programs "waive" some of the rules of Medicaid to serve children and adults otherwise requiring an institutional level of care who can; instead, be served at home or in the community. For example, if a child under the age of 18 with severe disabilities is ineligible for Medicaid because of parental income or resources, the state may waive this consideration in order to serve the child at home. Known as the Community Care Waiver ("CCW") and administered by the Division of Developmental Disabilities ("DDD"), this program provides case management, respite care, pre-vocational & day programming (including transportation); supported employment (including transportation); personal care assistant & training; environmental/vehicle adaptations (includes assistive technology devices; both of which are not to exceed $11,000 every three years); personal emergency response system; transportation and community transition services. New Jersey also offers several other Medicaid-funded waiver programs providing care in the home and community as an alternative to institutional care. For more information, contact the New Jersey Division of Disability Services ("DDS") or Department of Health and Senior Services ("DOHSS"). *See Important Resources.*

To learn more about Medicaid in New Jersey or in your state, contact the New Jersey Division of Medical Assistance & Health Services or Centers for Medicare & Medicaid Services ("CMS"). *See*

Important Resources.

Medicare is a partner program to Social Security, which provides a health and financial safety net to those 65 years and older and to those declared disabled for 24 months. Medicare is broken into several parts. Medicare Part A generally covers inpatient services – medical care when one is checked into a hospital or recovering in a nursing facility. It also covers some short-term home health care, along with hospice care. Most people are enrolled automatically in Part A when they reach age 65 and get it for free. Together, Part A and Part B are called "Original Medicare." Medicare Part B covers outpatient services – like physician visits and treatment at a hospital where one does not check in – along with lab tests and other medical care. Although enrollment in Part B is often automatic, it is not free. One is required to pay a monthly fee as well as an annual deductible.

Medicare Advantage plans are Medicare health plans that are managed by private insurance companies. All Medicare Advantage plans provide health care coverage. Some also offer prescription drug coverage and dental or vision care. These plans may cost more and restrict the doctors one can see.

Medicare Prescription Drug Plans (Medicare Part D) are optional plans that provide prescription drug coverage. The plans themselves are operated by private insurance companies; so, depending on one's plan, the costs and drugs covered vary. One must be careful when choosing a plan that makes the most sense for their individual circumstances.

Medigap policies are not part of Medicare; rather, they are private insurance plans that pay for health expenses (such as, treatments, supplements or co-payments) that Medicare does not cover. Medigap policies are operated by outside insurance companies and are at an additional cost to Medicare beneficiaries. The exact coverage and costs depend on the plan chosen.

For more information on Medicare, visit www.cms.gov.

4. The State Health Benefits Program ("SHBP") is provided to employees of the State and, like private employer-provided plans, is a fringe benefit of employment. There are, however, some important differences: generally the SHBP does not have to comply with state or federal insurance laws. Therefore, the SHBP can decide what to cover (or not) and in what quantity since they do not have to comply with the mandates of coverage set forth in New Jersey's insurance laws. As a result, SHBP plans offered to state employees vary greatly in their coverage.

For information about your state's SHBP, contact the New Jersey Department of Treasury, Division of Pensions & Benefits. *See Important Resources.*

B. Coordinating Coverage & Benefits

In addition to having a thorough understanding of your health care insurance coverage, you must also know who pays first for your child's health care and then communicate this information to your physicians and other providers. As a general rule:

- Private insurance, state-funded health benefits plans, and self-funded/self-insured plans typically pay first. If both parents have private insurance, it is important to file for coverage for your child under the one that best meets your needs. When selecting the primary private insurer, you may want to consider whether the plan covers dental care, out-of-network coverage, eye care and eyeglasses, and adaptive equipment.

- If your child is covered by Medicare in combination with other private insurance coverage, the first payer is not always clear. If your child is also covered by private insurance, primary coverage is determined by the size of the group covered under the plan. For example, if the coverage is under a large group health plan with less than 100 employees, Medicare pays first. If there are more than 100 employees, Medicare pays second. If you are covered by Medicare and Medicaid, Medicare pays first.

- If you are covered by more than one form of insurance (e.g., private insurance and Medicaid or Medicare), lack of proper coordination of benefits can also give rise to disputes.

For more information, visit www.cms.gov. *See also, Important Resources.*

C. Appeals Procedures

1. Most **private health insurance plans** provide three levels of appeal when a requested service is either denied, reduced, limited, or terminated or eligibility is terminated. The same is true for self-funded/self-insured plans. The three levels of appeal typically consist of two internal appeals – one informal, followed by a formal appeal – and an external appeal before a neutral arbiter outside of the health plan. Depending on the type of coverage, the external appeal could be heard by a medical review board, independent utilization review organization, state health benefits commission, state or federal agency, or an administrative law judge.

2. Medicaid Appeals are handled a little differently, depending on the nature of your coverage. For New Jersey State Medicaid Plan Appeals (a.k.a., Fee-for-Service plans), you may file for a Medicaid Fair Hearing when a covered health benefit has been denied, terminated or reduced. By law, you must receive written notice (that is, 10 days before the proposed action) any time there is a proposed change to your Medicaid benefits or services. Your request for a Fair Hearing must be filed in writing and within 10 days of the notice; and should clearly state the reasons you are appealing the proposed action. Once a timely appeal is filed, all Medicaid services must stay “as is” (status quo) until the final disposition of the appeal. In New Jersey, the Office of Administrative Law (OAL) conducts Medicaid Fair Hearings.

For Medicaid Managed Care Appeals, in addition to the Fair Hearing appeal right described above, a Medicaid beneficiary can also elect to follow the three levels of appeal afforded private health plans. *See above discussion*.

3. Medicare Appeals

Medicare Managed Care complaints are handled differently, depending on the nature of your complaint. A Medicare Grievance should be filed when you have a complaint relating to physician attitude, adequacy of facilities or time spent waiting for appointments. The Medicare Managed Care Organization ("MCO") must provide you with the procedure for filing a grievance in writing and must respond to your complaint in a timely manner.

A Medicare Appeal can be filed when the MCO denies, reduces or terminates services or payment for health services. The appeal process may be comprised of as many as five steps, which largely relates to the value of the disputed service, including (1) reconsideration either by the MCO or local Social Security Office; (2) independent organization review; (3) administrative law review; (4) departmental appeals board review; and (5) filing of a civil suit in Federal District Court.

The Medicare Peer Review Organization ("PRO") complaint process is for complaints regarding in-hospital stays. You may immediately request this review upon receiving written notice from the MCO or hospital that inpatient care is no longer necessary. Your request must be made either in writing or by telephone by noon of the first working day after receiving notice of discharge. The PRO has until the close of the business day on which it receives all necessary information from the hospital and MCO to issue a decision. You may stay in the hospital until noon after the day the PRO makes its final decision at no cost to you.

4. State Health Benefits Plans also have three stages of appeal. The first appeal is internal with the health insurance company administering the plan for the State of New Jersey. The second appeal is before the State Health Benefits Commission. The third appeal is before the OAL. Appeals from the OAL decision are heard by the New Jersey Superior Court, Appellate Division.

D. Health Care Reform Update

At the time of writing this booklet, the **Federal Health Insurance Reform** known as the Patient Protection & Affordable Care Act and Health Care & Education Affordability Reconciliation Act had only been passed into law a few months prior and the governing regulations were in the development stage. Here is what is known as of the writing of this booklet:

Starting as early as September 2010, job-based and new individual plans are not allowed to deny or exclude coverage to any child under age 19 based on a pre-existing condition, including a disability. Starting in 2014, these same plans will not be allowed to exclude anyone from coverage or charge a higher premium for a pre-existing condition including a disability.

Starting as early as September 2010, insurance companies are not allowed to drop an individual who gets sick just because he or she made a mistake on their coverage application.

Starting as early as September 2010, insurance companies cannot include lifetime limits on one's coverage.

Starting in 2014, most adults under age 65 with incomes up to about $15,000 per year for single individual (higher income for couples/families with children) will qualify for Medicaid in every state. State Medicaid programs will also be able to offer additional services to help those who need long-term care at home and in the community.

One may be able to join and get benefits from a voluntary, enrollment-based insurance program that will be available after October 2012 called the Community Living Assistance Services and Supports ("CLASS") Program. It will provide assistance to people who need help with daily activities. Under this voluntary program, one can get cash allowances so they can get care and other supports to help them keep their independence.

III. Supports & Services for Individuals Birth Through Age 21

A. Early Intervention Services (Birth through age 3)

Families of children from birth to age three who have disabilities, developmental delays, or special health care needs can receive Early Intervention Services ("EIS") for their child. In New Jersey, a child is eligible for EIS if he or she is under the age of three (3) and has at least a 33%

delay in one or a 25% delay in two or more developmental areas:

- Physical (gross & fine motor skills)
- Sensory (vision & hearing)
- Cognitive
- Communication
- Social or emotional
- Adaptive

In order to enroll and begin receiving Early Intervention Services from the State of New Jersey, call 888.NJEI.INFO or 888.653.4463. *See Important Resources.* For national information, visit The National Early Childhood Technical Assistance Center at www.nectac.org.

The purpose of Early Intervention is to strengthen parents' capacity to maximize their young children's development and learning. Early intervention (EI) provides services to infants and toddlers such as developmental education services, mental health services, and speech, occupational, and physical therapies to help children develop and grow. EI also provides services to families such as family support and education and helps connect families to respite and other services. EI providers work closely with families to help them understand their child's strengths and special needs, teach them to be an effective advocate for their child, and show them how to work with their child to maximize development in all areas.

Following an evaluation and assessment of strengths and needs, an Individualized Family Service Plan ("IFSP") is developed to describe the services that the child and family need, and how they will be implemented. The services should be based on the family's priorities, interests, and concerns, and the services should be provided in "natural environments" – that is, home, child care centers, and other community settings where infants and toddlers without disabilities are typically found. Services should be provided consistent with the family's routine. The need for a specific type of service is determined by an evaluation or assessment by a therapist from the area of concern. The frequency and intensity of services is determined by the entire IFSP team, including you, the parent, and other family members, friends, or service providers you want to include on the team.

Services include, but are not limited to, assistive technology, audiology services, health services (clean intermittent catheterization, tracheotomy care, tube feeding, the changing of dressings or colostomy collection bags, and consultation with service providers concerning special health care needs), medical services (diagnostic or evaluation services by a licensed physician to determine a child's developmental status and the need for early intervention services), nursing services, and nutrition. Other services may include occupational therapy, physical therapy, speech and language pathology, vision services (evaluation and assessment of vision, referral for medical or other professional services necessary for the habilitation or rehabilitation of visual functions), psychological services, and social work services, as well as family education, family support, and respite care.

Some EI services are provided at no cost to families regardless of family income, including an evaluation and assessment, service coordination, the development and review of an IFSP, and conflict resolution. All direct EI services are subject to a sliding fee scale for families at or above 350% of the Federal Poverty Level ("FPL") (the 2009-2010 FPL is $10,830 for an individual). *See the U.S. Department of Health & Human Services website at www.hhs.gov*.

B. Pre-school Disabled Program (Ages 3 through 5)

Pre-schoolers with disabilities who are found eligible for pre-school education after a comprehensive evaluation conducted by the school district are entitled to a free, appropriate public education in the least restrictive environment (that is, settings with non-disabled peers). This includes specialized instruction, which can be delivered in a typical early childhood program (such as a child care center), for at least 20 hours per week, as well as any needed related services. Related services for pre-schoolers include, but are not limited to, speech, occupational, and physical therapy; counseling; and transportation. Services are provided throughout the school year unless your child needs extended school year services (that is, services during summer months). All special education and related services are included in the Individualized Education Program ("IEP") that you will develop with the school district's Child Study Team.

For more information, contact the New Jersey Department of Education or U.S. Department of Education. *See Important Resources.*

C. Special Education (Ages 5 through 21)

Pre-school programs for children with disabilities ages 3-5 (*discussed above*) and special education programs for children ages 5-21 are provided under federal and state law. Families can write to their local school district to request an evaluation for eligibility for pre-school and school-age special education services. If the family disagrees with the evaluation results, they may request an independent evaluation be done also at the school district's expense.

Children between the ages of 5 and 21 with disabilities that negatively affect learning are entitled to special education services at no cost to parents. These services are federally mandated in all states. It is the responsibility of local school districts to provide these services.

School districts are responsible for identifying, evaluating, and then classifying children with disabilities as eligible for special education and related services. State regulations set forth time lines and the methods to accomplish this, as well as administrative procedures to resolve any disputes.

Federal law requires that each child must receive a program that meets his or her unique and individual needs. School district Child Study Teams must partner with parents to annually develop a written IEP that outlines the services to be provided with measurable goals and objectives. For some children, the IEP might involve modifications of curriculum, instructional strategies, or classroom arrangement as well as individual instruction or related services and therapy. Other children might need placement in a specialized class or placement in a private school that specializes in serving children with a particular type of disability. Private schools can provide services on a day or a residential basis. Depending on need, children might be entitled to additional educational services over the summer months otherwise referred to as extended school year services.

Children may be eligible for related services as part of their IEP. Related services may include speech therapy, occupational therapy, physical therapy, counseling and psychiatric/psychological services, transportation training, and school-based nursing services, among others.

School districts must document a child's strengths and special education needs as well as his or her progress in school. Evaluations and other records can be helpful later in life to determine eligibility for adult services and other government assistance programs.

For more information about the laws that govern special education services in the State of New Jersey, visit: www.state.nj.us/education/code/current/title6a/chap14.pdf. For information in your state, visit www.ed.gov.

IV. Entitlements for Adults with Disabilities

A. State Disability Benefits

1. For Individuals with Developmental Disabilities (Lifetime)

In New Jersey, the primary funding source for services for adults with disabilities once special education services end – that is, once the child either is graduated between ages 18 and 21 years of age, or ages out at age 21 – is the New Jersey Division of Developmental Disabilities ("DDD"). That being said, DDD also provides some services to children under the age of 18.

Eligibility for DDD is defined by New Jersey state statute. To be eligible, one must have a mental or physical impairment that occurred before age 22, and which substantially impairs at least three (3) of the following areas of major life activity:

- Self-care
- Learning
- Mobility
- Receptive & Expressive Language
- Self-direction
- Capacity for Independent Living
- Economic Self-sufficiency

See www.acf.hhs.gov/programs/add/ddact/DDCT2.html *for the Federal DD Act.*

Services from DDD for adults include case management services, adult day programs, residential placement, and employment services. Services are often provided at no cost to the family and can be provided over the lifespan of the individual. Fees for some services may apply to individuals who have an income or to families when a dependent child under the age of 18 receives residential services from DDD.

For children and youth under the age of 18, DDD provides family support services. These may include behaviorists, summer camp, cash subsidies, communication and interpreter services, counseling and crisis intervention, day care, equipment and supplies, home and vehicle modifications, homemaker assistance, medical and dental care, personal assistance services, therapeutic or nursing services, and respite. These services are limited to funds available.

It is important to make sure your child is on the residential waiting list upon receiving an eligibility determination from DDD.

For information in your state, contact DDD. *See Important Resources*. For more information on the national level, contact the U.S. Department of Health & Human Services, Administration on Developmental Disabilities at www.acf.hhs.gov/program/add.

2. Vocational & Rehabilitation Services (Ages 18 and older)

In New Jersey, the Division of Vocational Rehabilitation Services ("DVRS") provides services to adults with a variety of disabilities. In order to be eligible for services from DVRS, one must have a physical or mental impairment that is a substantial impediment to employment. Unlike the services provided by DDD (*as discussed above*), DVRS's services are limited to employment and employment-related training and are geared toward successful employment. Services from DVRS include vocational evaluations, individual vocational counseling and guidance, job-seeking training skills, job-coaching, follow-up and post-placement services, physical restoration, job training, and higher education. Not all of these services are free of charge. DVRS's services are of limited duration.

For information in your state, contact DVRS. *See Important Resources.* For information on the national level, visit the Office of Special Education and Rehabilitation Services at http://www2.ed.gov/about/offices/list/osers/rsa/index.html.

B. **Federal Benefits from The Social Security Administration**

Supplemental Security Income (SSI) is available to people whose disabilities prevent gainful employment. In order to be eligible, an individual must not have greater than $2,000 in countable resources and less than approximately $668 in monthly income (*varies by state*). Because the income and resources of parents are counted until the child turns 18, many people with disabilities will not qualify for SSI until they have reached the age of 18. After age 18, the income and resources of family members are not counted even if the individual continues to live at home. The SSI benefits usually ranges between $500.00 and $700.00 per month. The monthly amount depends on a number of factors, including where the person lives and what other income he or she may have.

In most states, individuals who qualify for SSI automatically receive Medicaid (a.k.a., Medical Assistance). Medicaid pays for a wide array of services for people with disabilities and provides government-funded health insurance for children and adults with disabilities who have limited financial resources. Medicaid also provides government funding for long-term services and supports, including institutional care in nursing facilities and, in some cases, in non-specialized placements for people with disabilities.

Social Security Disability Insurance (SSDI) pays benefits to covered workers who are unable to work because of a disability. After two years, the worker qualifies for Medicare. SSDI is typically given to workers who sustain injuries; however, sometimes, people with lifelong disabilities or mental illness qualify because of work history and experience a subsequent problem with continued employment.

Benefits for Disabled Adult Children are available to adults who are unmarried, 18 years of age or older, and whose disability started before the age of 22. One is eligible where their parent has retired (and is collecting their own Social Security Retirement Benefits), has become disabled (and is collecting their own SSDI benefits), or is deceased. The amount of this benefit paid to the disabled adult child is based on the parent's Social Security earnings record. While the disabled adult child may still work and qualify for these benefits, his or her earnings must not be "substantial". In 2010, substantial earnings were considered to be greater than $1,000 per month.

Social Security Retirement (SS) Benefits are available to workers would have earned the requisite 40 Social Security credits. Individuals with disabilities who are considered dependents of a parent collecting SS benefits or of a parent who dies may be entitled to receive a greater monthly benefit amount from the Social Security Administration (SSA) under that parent's earnings record. Additionally, individuals who receive SS benefits receive Medicare two years after SS benefits begin.

V. Future Planning Considerations

A. Estate Planning (Lifetime)

A Last Will & Testament sets forth who will receive your property at death. It also is the tool through which one appoints the Executor/Executrix of their Will, Trustee of any Trusts created under the Will and, where applicable, who will serve as guardian of their children. The Executor/Executor is the one who will ensure that your wishes are followed; whereas, the Trustee will receive, invest, manage, and disburse any funds directed into a Trust created under the Will for the lifetime of the beneficiary. The Guardian is the one who manages the affairs of your minor, incapacitated or disabled children.

Wills executed in one state are generally effective in another state; however, since tax laws differ by state, it is a good idea to have your Will reviewed by an attorney if you move into a new state.

When one does not have a Will, the state laws of intestacy govern how your assets will be distributed to your family. Generally, your next of kin will receive your property.

B. Special Needs Trusts (Lifetime)

Most parents want to leave assets to their children when they die; however, if a person with a significant cognitive disability receives assets, they may not have the capacity to make good decisions about how those assets are used and they may become ineligible for important federal and state resources and services. The person will lose Medicaid and SSI and the assets may also be subject to recoupment by Medicaid or by the State if the person is receiving residential services.

This sometimes leads to parents disinheriting their 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 can have equally negative results.

To avoid these negative consequences, it is recommended that parents establish a Special Needs Trust ("SNT"). A SNT can protect the assets while, at the same time, making the assets 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. It must be carefully worded and is best written by professionals familiar with disability services and programs.

Parents and other family members can use a SNT to hold assets for a disabled person. Even families with modest assets should establish a trust. Typically such trusts are not funded until one or both parents die. A SNT can be funded through life insurance or estate assets distributed through one's Will. So long as the assets have never vested in the person with a disability, the SNT need not contain a provision reimbursing Medicaid or other providers.

Trust funds can be used to purchase independent professional opinions as necessary, fill in gaps in services, provide additional recreation and other amenities, pay for a private residential placement or buy a vehicle used to transport the beneficiary of the trust.

At the death of the beneficiary, any remaining trust property is disposed according to the instructions written in the trust document by the Grantor or Settler. For example, property might go to other family members or to a charity.

The governing regulations for special needs trust can be found at N.J.A.C. 10:71-4.11 and 42 U.S.C. §1396p.

C. Guardianship (Age of Majority)

In the eyes of the law, even a person with a significant developmental, cognitive or mental health disability is legally permitted to make decisions on his or her own behalf at the age of majority. Therefore, if a person is not capable of making his or her own decisions or managing his or her affairs due to a significant disability, it is necessary to secure the court appointment of a guardian.

A guardian is someone appointed by the court to make decisions on behalf of another person who cannot make decisions independently. There are two types of guardians: a guardian of the person and a guardian of the property. A guardian of the person 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 the individual’s personal finances. That being said, a guardian of the property does not have control over assets held in trust unless the guardian is also the trustee.

In order to obtain guardianship, the court must first find that the person cannot make decisions about him/herself or manage his/her property. If the court determines this to be the case, it will appoint someone to take on this responsibility; in most cases, one or both parents. The court may also appoint a brother or sister to serve as guardian with the parents, or alone, after the parents have died. Once parents have secured guardianship for an adult child, they can appoint a successor guardian in their Will or can temporarily delegate guardianship through their Power of Attorney.

The guardian's job is to make decisions in the best interest of the person under guardianship. A guardian does not bear any risk for the ward's acts or financial debts and is under no legal obligation to provide direct care or housing to the person.

In addition to full plenary guardianship, the State of New Jersey recognizes limited, or partial guardianship. This allows the person with a disability to make certain decisions (e.g., voting) while specifying those decisions that can only be made by their guardian. It is important for parents to consider the value of maximizing their child's independence and ability to make decisions on their own behalf when thinking about applying for guardianship. Even if parents seek and are granted guardianship, the person with a disability should have the opportunity to participate as much as possible in decision-making.

VI. Important Resources

EDUCATION
NJ Department of Health and Senior Services
Early Intervention System
P.O. Box 360
Trenton, NJ 08625-0360
888.653.4463
http://www.njeis.org
http://nj.gov/health/fsh/eis/index.shtml

NJ Department of Education
Office of Special Education Programs
P.O. Box 500
Trenton, NJ 08625
609.292.4469
www.state.nj.us/njded

U.S. Department of Education
400 Maryland Avenue, SW
Washington, D.C. 20202
1.800.USA.LEARN (1.800.872.5327)
http://www.ed.gov/

EMPLOYMENT / LABOR
NJ Department of Labor & Workforce Development
Division of Disability Determination Services
P.O. Box 382
Trenton, NJ 08625-0382
800.772.1213
http://www.state.nj.us/labor/dds/ddsforms.html

NJ Department of Labor & Workforce Development
Division of Vocational Rehabilitation Services
P.O. Box 398
Trenton NJ 08625-0398
609.292.5987
609.292.2919 (TTY)
www.state.nj.us/labor/dvrs

FEDERAL
The Social Security Administration
Visit the SSA website or call to locate your nearest office.
http://www.socialsecurity.gov
800.772.1213

HUMAN SERVICES
NJ Department of Human Services
Division of Developmental Disabilities
P.O. Box 725
Trenton, NJ 08625-0725
800.832.9137
http://www.state.nj.us/humanservices/ddd/index.html

INSURANCE
NJ Department of Banking & Insurance
P.O. Box 325
Trenton, NJ 08625-0325
800.446.7467
www.njdobi.org

U.S. Department of Labor
200 Constitution Ave., NW
Washington, DC 20210
1.866.4.USA.DOL (1.866.487.2365)
http://www.dol.gov/dol/contact/

NJ Department of Health & Senior Services
P.O. Box 360
Trenton, NJ 08625-0360
800.328.3838
www.state.nj.us/health

State Health Benefits Coordination
New Jersey Department of Treasury,
Division of Pensions & Benefits
P.O. Box 295
Trenton, NJ 08625-0295
609.292.7524
http://www.state.nj.us/treasury/pensions/shbp.htm

LEGAL
NJ Office of Administrative Law
P.O. Box 049
Trenton, NJ 08625-0049
609.588.6501
http://www.state.nj.us/oal/general.html

MEDICAID
NJ Department of Human Services
Division of Medical Assistance & Health Services
Quakerbridge Plaza
P.O. Box 712
Trenton, NJ 08625-0712
800.356.1561
http://www.state.nj.us/humanservices/dmahs

The Centers for Medicare & Medicaid Services
7500 Security Boulevard
Baltimore, MD 21244
800.MEDICARE (800.633.4227)
www.cms.gov

MEDICARE
See above for The Centers for Medicare & Medicaid Services

New Jersey State Health Insurance Programs (SHIP)
Department of Health and Senior Services
P.O. Box 360
Trenton, NJ 08625-0360
609.292.7837
1.800.367.6543 *(Toll free in NJ)*
1.800.792.8820 *(SHIP Information Center)*
http://www.state.nj.us/health/senior/ship.shtml

TURNER SYNDROME

Turner Syndrome Foundation, Inc.
P.O. Box 726
Holmdel, New Jersey 07733
www.TurnerSyndromeFoundation.org
800.594.4585 *(toll free*)
800.594.3862 (*facsimile*)

VII. About the Author

Valerie A. Powers Smith, Esq., Of Counsel at **Slovak Baron & Empey, LLP**, has practiced for over thirteen years in the area of special needs and disability law throughout New Jersey and Pennsylvania**.** Over this time, Valerie has focused her law practice in the following highly specialized areas: health care insurance, disability insurance, Medicaid, Medicare, special needs trusts, trust administration, estate planning & administration, guardianships, and accessing federal and state government disability-based benefits.

In particular, Valerie has concentrated her legal work in the area of health care law and has vigorously advocated for families and people with disabilities to gain medically necessary care from private insurance companies, Medicaid, Medicare, and other health insurance providers. She has additionally focused her practice in the areas of special needs trusts and estate planning and routinely advise families, executors, and trustees on the area of special needs law and the administration of the trusts and estates.

Valerie has written extensively on a variety of disability law topics, has co-authored several publications on accessing adult services, Medicaid, and health insurance; and is a regular contributor to the Arc of New Jersey's Healthy Times and Caregivers of New Jersey Newsletters. She also lectures for disability-related groups throughout Pennsylvania, New Jersey, and Washington, D.C. Valerie currently sits as one of the 12 members appointed by the Governor to the New Jersey Medical Assistance Advisory Council and is serving her second three-year term. She is also a member of the

Board of Directors for Easter Seals of Southeastern Pennsylvania, Caregivers of New Jersey, NAMI Mercer New Jersey, and Desert Friends of the Developmentally Disabled in California. She is also an Advisory Board Member of Family Voices New Jersey and Autism Family Services of New Jersey. On the national level, Valerie serves as a legal consultant for MITO ACTION; and is on the legal advisory board for the Turner Syndrome Foundation, Inc.

Valerie can be contacted at Slovak Baron & Empey at either the below-listed New Jersey or California addresses or via email at powers@sbemp.com.

VIII. Acknowledgements

The Turner Syndrome Foundation wishes to thank Valerie A. Powers Smith, Esq., Slovak Baron & Empey, LLP, for her time and expertise given writing and editing this booklet.

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Palm Springs, California 92262
760.322.2275*(telephone)*
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