

# Health Care Advocacy Across the Lifespan

What Parents of Children  
with Disabilities Need to Know



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Stephanie,  
my inspiration

## Letter From Family Voices

I am a parent of a child with multiple disabilities. My daughter, Stephanie, is medically fragile due to kidney disease. She also has autism and other special healthcare needs, all of which require special medical attention.

My first rude awakening to the medical system occurred when I followed the guidelines for therapy under both my husband's and my insurance. I checked both employee handbooks and called both to verify it would be covered. I had a physician's note and used only approved and certified therapists. However, when I sent my claim in, it was denied by both insurers. I fought for one and a half years and eventually won the appeal.

Insurance companies depend on people giving up and going away. Only one third of families appeal denials of claims even though half of the appeals are granted on the first attempt. If you are told "no" over the telephone or receive a written explanation of benefits for a denial, do not give up. I became an advocate for children with special health care needs because I constantly struggled with the medical and, later, educational systems that were supposed to help my child and family. I did not want families in similar situations to suffer the same hardships. I hope you find this booklet helpful in making sure that your child receives the health coverage and healthcare he or she needs.

Lauren Agoratus, M.A.

Parent (my most important title),

New Jersey Coordinator, Family Voices-NJ at the Statewide Parent Advocacy Network,  
Volunteer, New Jersey Caregiver Community Action Network-National Family Caregivers

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## Introduction & Overview

Parenting a child with special health care needs is not an easy task. The 40,000 members of Family Voices, mostly parents, want you to know that you are not alone. We have learned that the sooner we become advocates – informed, strong voices for our children – the smoother life becomes for our children and families. Here are some advocacy tips:

- ❶ Learn everything you can about your child’s diagnosis. Once you know what you are dealing with, you will be empowered to make decisions.
- ❷ Connect with another family who also has a child with special needs.
- ❸ Be informed about your child’s health insurance plan and the benefits covered, as well as, additional coverage available through, alternate public and private programs.
- ❹ Keep records of all telephone calls, physicians visits, insurance forms, and copies of any paperwork related to your child’s health care.
- ❺ Partner with professionals to maximize your child’s care for the best outcome. Know that YOU are your child’s best advocate and teach your child to be an advocate.

\*Adapted from Family Voices national fact sheet [www.familyvoices.org](http://www.familyvoices.org)

Health insurance is a complex system. A complete understanding of your coverage is critical to securing all the services your child needs, and a way to learn about other programs through which your child could also obtain coverage. The more you know, the more you will maximize coverage and minimize your financial responsibility. Moreover, dependents 30 years and younger must be provided coverage under New Jersey insurances mandates where other group health insurance is unavailable.

This booklet will help you as you work to access care through a variety of health care service systems. Other sources providing children primary or additional coverage for a particular therapy or service include Early Intervention Services (Birth - 3), special education services from your local school district (3-21 years of age), and state disability programs (all ages).

Looking ahead, under most private insurance plans, parents can continue coverage for dependent adult children with disabilities; however, parents should check their plan’s language for the necessary requirements – typically, proof of disability – to extend private dependent coverage to a child with a disability.

From time to time, health care plans may reduce, limit or deny coverage. When this occurs, it is vital that parents know their appeal rights and exercise them in a timely manner.

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## Things You Need to Know about Your Health Care Coverage

- 1 What type of health insurance plan you have.
- 2 Other forms of coverage to which you or your child may be entitled.
- 3 How to coordinate benefits.
- 4 The extent of coverage your health insurance plan provides.
- 5 Who (that is, physicians and facilities) can provide care under your plan(s).
- 6 How to access specialists and out of-network providers.
- 7 The referral process.
- 8 Your financial responsibilities.
- 9 The appeals process.
- 10 The complaint and grievance processes.

## Considerations Throughout the Lifespan

### Early Intervention System (Birth to 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 and has at least a 33% delay in one or a 25% delay in two or more developmental areas:

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

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**To start early intervention services in New Jersey, families must call (888) NJEI-INFO or (888) 653-4463.**

Service coordinators from Special Child Health Services (SCHS) at (609) 777-7778 assist with early intervention for eligible infants and toddlers and their families. Children with special healthcare needs can have a case manager at no cost from SCHS from birth to age 21. They can help families prepare and submit a “universal application” for services from a range of state agencies, including early intervention from the Department of Health and Senior Services; special education from the Department of Education; respite care, cash assistance, camp funds, behaviorist services, and any special equipment from the Division of Developmental Disabilities; services from Medicaid and Family Care; and funding from the Catastrophic Illness in Children Relief Fund.

The purpose of early intervention under the federal Individuals with Disabilities Education Act (IDEA) 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.

Public and private agencies serve as providers. 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.

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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.

EI is funded in part by the New Jersey Department of Health and Senior Services, with state and federal funds. Some 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 Individualized Family Service Plan (IFSP), and conflict resolution. All direct early intervention services are subject to a sliding fee scale for families at or above 350% of the Federal Poverty Level (FPL).

For autism guidelines for early intervention, visit the website [www.njeis.org/familylink/autism/auguide.pdf](http://www.njeis.org/familylink/autism/auguide.pdf)

### **ADVOCACY TIP:**

If families have problems or concerns about early intervention services, they can reach the family support coordinator at their Regional Early Intervention Collaborative (REIC) at [www.njeis.org](http://www.njeis.org) or the early intervention procedural safeguards coordinator at (609) 777-7734 or they can contact the federally funded Parent Training and Information Center and Family to Family Health Information Resource Center, the Statewide Parent Advocacy Network (SPAN) at 800-654-SPAN or [www.spannj.org](http://www.spannj.org).

### **Pre-school Disabled Program (3-5 years of age)**

Both pre-school programs for children with disabilities ages 3-5 and special education programs for children ages 5-21 are under the Individuals with Disabilities Education Act (federal law), as well as, the NJ Administrative Code (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 district's expense.

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### **ADVOCACY TIP:**

There is now a requirement for a parent special education group in each district. Local parent groups can be found at [www.spannj.org/START](http://www.spannj.org/START). Your local special education parent advisory council can help you with information on how to get started and what to do if you are having problems.

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 (i.e., 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 can include speech, occupational, and physical therapy, counseling, transportation, etc. Services are provided throughout the school year unless your child needs extended school year services (services during summer months). All special education and related services are included in the individualized education program (IEP) that you will develop with the district's Child Study Team. (For more information, see Special Education, below).

### **ADVOCACY TIP:**

It is important for you to get your child's therapies under special education rather than using your health insurance so as to reduce the therapies counting against your child's "lifetime cap." Note: insurance companies limit services for your child's lifetime while getting services through your school district does not. If you are income-eligible for Medicaid, your district may ask you to sign consent to get Medicaid to cover related services that they provide; but you do not have to give your consent. The district must still provide the services your child needs even if you refuse your consent for Medicaid to cover them.

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## Special Education (5-21 years of age)

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, with oversight provided by the New Jersey Department of Education, 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 Individualized Education Program (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.

Governing state special education regulations: [www.state.nj.us/education/code/current/title6a/chap14.pdf](http://www.state.nj.us/education/code/current/title6a/chap14.pdf)

Autism guidelines for special education: [www.nj.gov/education/specialed/info/cosac\\_files/frame.htm](http://www.nj.gov/education/specialed/info/cosac_files/frame.htm)

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## The New Jersey Division of Developmental Disabilities (DDD) (Lifespan)

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 DDD, a Division within the New Jersey Department of Human Services. DDD also provides some services to children under age 18.

**Eligibility for DDD** is governed by state statute. To be eligible, a person must have a mental or physical impairment that occurred before age 22, and which substantially impairs at least 3 of the following 6 areas of major life activity:

- self-care
- learning
- mobility
- receptive and expressive language
- self-direction
- capacity for independent living
- economic self-sufficiency

Services from DDD for adults include case management services, adult day programs, residential placement, and vocational 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, 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.

## The New Jersey Division of Vocational Rehabilitation Services (DVRS) (Ages 18 and older)

DVRS also provides services for adults with disabilities. To be eligible for DVRS services, an individual must have a physical or mental impairment that is a substantial impediment to employment. DVRS's

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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.

## **New Jersey Division of Child Behavioral Health Services (DCBHS) (Lifespan)**

DCBHS, within the Department of Children and Families (DCF), serves children and adolescents with emotional and behavioral health care challenges and their families. DCBHS strives to provide these services based on the needs of the child and family in a family-centered, community-based environment.

DCF provides a virtual single point of contact that registers, tracks, and coordinates care for children who are screened – at any level – into its Children's Behavioral Health Service System of Care. DCF contracts with Value Options, a private entity, to administer this service system.

DCBHS provides:

- Mobile Response and Stabilization Services
- Care Management Organizations
- Youth Case Management Services
- Family Support Organizations
- Training and technical assistance services to families

For questions about or to access services for children and youth, call the 24-hour, toll-free Access Line at 877.652.7624.

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## The Social Security Administration (SSA) (Ages 18 and older)

**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 must have less than approximately \$668.00 (2008) in monthly income. 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 range between \$450 and \$650 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.

Individuals who qualify for SSI are eligible to receive Medicaid. 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.

**Social Security Survivor's Benefits** are available to disabled dependents of a parent who collects Social Security benefits or who dies. Individuals who receive Social Security also receive Medicare. Social Security benefits count as income for SSI purposes and, in some cases, can reduce or eliminate SSI benefits.

## Estate Planning (Lifespan)

A Will establishes who will receive your property at death. It also establishes, where applicable, who will serve as guardian of your children. A will also establishes who will see that your wishes are carried out. Wills executed in one state are usually good in another. Since tax laws of each state vary, it is a good idea to have your Will reviewed by an attorney if you move into a new state.

What happens if there is no Will? This is called intestacy. Contrary to what many believe, the government does not get your property if you die without a Will. The laws of the state in which you reside at the time of death determine who will get your property. Generally, this will mean that your next of kin will receive your property. Property will only go to the state if there is no next of kin.

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## Special Needs Trusts (All ages)

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 is what is sometimes referred to as a 'gift of moral obligation' and it can have equally negative results.

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. The spouse of the non-disabled child may want to use the assets for other purposes not related to the sibling with a disability. Even if the non-disabled sibling uses the assets exactly as the parents intended, they can be claimed by creditors, can have negative tax consequences on the non-disabled sibling, and can be subject to equitable distribution in the event of divorce.

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 and 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 donor. For example, property might go to other family members or to a charity.

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## 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 due to a significant disability, it is necessary to secure the judicial 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 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. They do not, however, have power over assets held in trust unless the guardian is also the trustee.

In order to have this authority, the court must first find that the person cannot make decisions about him/herself or 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. (The court cannot force someone to serve as a guardian if they do not wish to do so). Once they have secured guardianship for an adult child, parents can appoint a successor guardian in their Will, or can temporarily delegate guardianship through a written document called a power of attorney.

The guardian's job is to make sure that the person with a cognitive disability or mental illness is to make decisions in the best interest of the person under guardianship and make sure he or she is safe. The guardian does not bear any risk for the person's acts or debts and is under no legal obligation to provide direct care to the person. There is no downside to serving as a guardian.

The State of New Jersey now recognizes "limited" guardianship. This allows the person with a disability to make certain decisions 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.

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## Other Future Caregiver Planning

Even the best plans for a person with a disability can be upset if one or both parents need to enter a nursing home. Long Term Care Insurance (LTCI) can be used to pay for nursing home services, as Medicaid and standard medical insurance do not cover an extended stay. Although it can be expensive, in many cases, LTCI is worthwhile, and it 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 disabilities.

It should also be noted that there is a unique provision in the federal Medicaid law allowing a parent to transfer funds to a disabled son or daughter and still qualify for Medicaid. Great 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 is often needed.

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## Understanding Your Health Care Insurance Coverage

There are several types of insurance coverage:

- Private insurance (including 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.

**Private Insurance** is provided by your employer or obtained on your own. Plans are governed by New Jersey law and enforced by the New Jersey Department of Banking and Insurance. 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.

**Self-Funded/Self-Insured Plans** are insurance plans offered by a private employer, in which the employer (not an insurance company) assumes the risk of insuring its employees. Under such arrangement, the employer hires an insurance company to administer the plan and handle all of the claims. These types of plans have greater latitude as to what they do and do not cover.

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

**Medicaid** 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, approximately \$668.00 or less in monthly income and no more than \$2,000 in countable assets).

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

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In addition, each state may elect to include any of the following Optional Services:

- Residential Treatment Centers
- Dental
- Chiropractic
- Podiatrist
- Drugs during long-term care
- Hearing Aides
- Transportation
- Personal Care services
- Therapies (ST, OT & PT)
- In-patient psychiatric care for under 21 & older than 65
- Optical appliances
- Optometry
- Psychology
- Prosthetics & Orthotics
- Durable Medical Equipment
- Hospice
- Private Duty Nursing services
- Clinic services
- Intermediate care (ICF/MR)

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 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. Covered services under the EPSDT Program may 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, medically necessary orthodontic care, and personal care services.

In order to obtain and maintain coverage, your treating physician must provide written documentation that the requested service is medically necessary. 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 (HCBW) Programs provide individuals with disabilities 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

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## A note about Medicaid Managed Care

Under the Medicaid Managed Care System, patients generally wait longer for care and often have limited use of specialists. And, as managed care organizations have gained responsibility in the area of behavioral mental health care, there has been concurrent increase in concerns regarding access to psychiatric and mental health services. Like others who receive Medicaid, many adults with disabilities have been transitioned into managed care plans. For individuals who have unique health care needs and require coordination by experienced providers, this can be detrimental when needs are not met. Under these circumstances, requesting exemption from the Medicaid Managed Care System may be recommended. Exemptions are granted upon request.

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 DDD, this program provides case management, respite care, day habilitation (including pre-vocational & day programming and transportation); supported employment (includes transportation); individual supports (personal care assistant & training); integrated therapeutic network (ITN) therapies (including OT, ST, PT & psychological services; environmental/vehicle adaptations (includes assistive technology devices; both of which are not to exceed \$11,000 every three years); personal emergency response system (PERS); transportation; 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, which are administered by the New Jersey Division of Disability Services (DDS) and Department of Health and Senior Services (DOHSS). (See Resources section for contact information.)

Choosing the right Medicaid Program is critical to receiving the right care. Medicaid has a number of programs and selecting the one best meeting your needs can be a challenge. Relevant in the decision-making process is whether your child's physicians participate, and whether you are willing to change physicians. In some cases where enrollment in Medicaid Managed Care is mandatory, you may request an exemption to remain in the Medicaid Fee-for-Service system.

**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 divided into two parts. Part A covers hospital and limited nursing care. Part B, which requires an extra premium, covers physician services, as well as a variety of therapies and other items. Medicare also has co-payments and deductibles.

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**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:

- SHBP is not subject to oversight by the New Jersey Department of Banking and Insurance or the U.S. Department of Labor.
- SHBP can decide what to cover – or not – and in what quantity since they do not have to comply with the mandates of New Jersey’s insurance laws.
- SHBP plans offered to state employees vary greatly in their coverage.

## The Role of Case Managers

Case managers play a key role in determining what procedures are covered under any insurance contract, public or private. If a procedure is deemed “not covered” by the case manager, you may appeal. The health plan’s medical director must use all available information to determine whether a medical procedure being submitted for payment is medically necessary for the health and well-being of a patient. It is during this appeals process that the medical director for the insurer examines the information provided and determines whether it meets the qualifications for medical necessity. The National Policy Center for Children with Special Health Care Needs has developed a document on medical necessity that could assist insurers with defining medical necessity for persons with special health care needs.

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## Coordination of Coverage: Who Pays First?

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:

- ❶ 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.
- ❷ If your child is covered by Medicare in combination with other private insurance coverage, the first payer is not always clear. For example:
  - If you are covered by Medicare and Medicaid, Medicare pays first.
  - Medicare pays second if your other coverage is a private plan.
  - 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 claim comes from a large group health plan with less than 100 employees, Medicare pays first. If there are more than 100 employees, Medicare pays second.

## Appeal Procedures

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.

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### **Disputes that may give rise to an appeal include:**

- Denial of payment for a medically necessary covered benefit
- Reduction, denial or termination of a covered service
- Denial or termination of eligibility

### **Private Health Insurance Plan Appeals**

Under New Jersey law, beneficiaries of private, managed care plans have three levels of appeal – two internal appeals within the insurance company and a third external review before an independent utilization review organization (IURO). The third level, external appeal decision of the IURO is binding on all parties.

If you have a complaint about quality of care under a private insurance plan, you may file a grievance with the member services department within your health plan. Typically, you should receive a response within 30 days. If you are not satisfied with the decision, you may contact either the New Jersey Department of Banking & Insurance or Department of Health & Senior Services to complain. (See Resources Section for addresses)

### **Self-Funded/Self-Insured Plan Appeals**

Self-funded/Self-insured plans have significant latitude as to what they do and do not cover. There is no internal appeals process or state agency involved with these appeals. Appeals must be filed with the U.S. Department of Labor.

### **Medicaid Appeals**

#### ***New Jersey State Medicaid Plan Appeals***

As a Medicaid beneficiary, 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 (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

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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.

The New Jersey Office of Administrative Law (OAL) conducts Medicaid Fair Hearings. OAL prefers that you proceed to the second level internal appeal before filing for a Medicaid Fair Hearing. However, if you have problems getting the HMO to maintain your services during the appeal, filing the Medicaid Fair Hearing appeal while indicating that the internal appeal process is also underway may be appropriate.

### ***Medicaid's Managed Care System Appeals***

As a Medicaid Managed Care beneficiary, in addition to the Fair Hearing appeal right, you can also choose to follow the above-described 3-stage appeal process for private health plans, where covered health benefits have been denied, limited or terminated.

If you are covered under a Medicaid managed care organization, you may file a grievance or appeal with the Medicaid HMO in several ways: First, you may file a grievance with your HMO complaining about quality of care issues, as well as any denial, termination or reduction in your Medicaid benefits. In an emergency situation, you must receive a decision regarding your grievance within 24-48 hours (Note: in such a situation, you must request an “urgent review”). Otherwise, decisions must be made by the HMO within 90 days of the filing of your complaint.

## **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.

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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.

### **State Health Benefits Program Appeals**

SHBP beneficiaries have two internal appeal levels, and a third external appeal level before the State Health Benefits Commission (SHBC). The decision of the SHBC is final but may be appealed to Office of Administrative Law.

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## Resources

### **NJ Department of Banking & Insurance**

P.O. Box 325  
Trenton, NJ 08625-0325  
800.446.7467  
[www.njdobi.org](http://www.njdobi.org)

### **NJ Department of Health & Senior Services**

P. O. Box 360  
Trenton, NJ 08625-0360  
800.328.3838  
[www.state.nj.us/health](http://www.state.nj.us/health)

### **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>

### **NJ Department of Labor & Workforce Development Division of Disability 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](http://www.state.nj.us/labor/dvrs)

### **NJ Department of Education Office of Special Education Programs**

P.O. Box 500  
Trenton, NJ 08625  
609.292.4469  
[www.state.nj.us/njded](http://www.state.nj.us/njded)

### **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>

### **NJ Department of Children & Families Division of Child Behavioral Health Services**

50 East State Street, 4th floor  
P.O. Box 717  
Trenton, NJ 08625-0717  
609.292.4741  
24-hour, toll-free Access Line 877.652.7624  
<http://www.nj.gov/dcf/behavioral>

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**State Health Benefits Coordination  
NJ Division of Pensions and Benefits**

P.O. Box 295  
Trenton, NJ 08625-0295  
609.292.7524  
[http://www.state.nj.us/treasury/pensions/  
shbp.htm](http://www.state.nj.us/treasury/pensions/shbp.htm)

**NJ Office of Administrative Law**

P.O. Box 049  
Trenton, NJ 08625-0049  
609.588.6501  
<http://www.state.nj.us/oal/general.html>

**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>

**The Social Security Administration**

Visit the SSA website or call to locate your nearest office.  
<http://www.socialsecurity.gov>  
800.772.1213

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## About the Authors

**Valerie A. Powers Smith** is a member of the law firm of Hinkle, Fingles & Prior and has focused her legal career on representing people with disabilities and their families. She has concentrated her work on health care law and has vigorously advocated for families and people with disabilities to gain medically necessary care from private insurance companies, Medicaid, and other health insurance providers. Valerie also practices in the areas of guardianship, estate planning and administration, special needs trusts, and government disability services. She has written extensively on a variety of disability law topics, and has co-authored several publications. She is a regular contributor to the Arc of New Jersey's Mainstreaming Medical Care Newsletter, Healthy Times. She lectures frequently for disability groups throughout Pennsylvania and New Jersey. Valerie is currently serving her second, 3-year Governor-appointed term on the the New Jersey Medical Assistance Advisory Council. She is a member of the Board of Directors of CareGivers of New Jersey and Easter Seals of Southeastern Pennsylvania, and serves on the advisory council for Family Voices of New Jersey and Autism Family Services of New Jersey. She also serves as a national consultant for MITO Action. Valerie is the former Director of the Health Care Consumer Assistance Program and member of the advisory board of the Bucks County ARC. Valerie holds a J.D. from Widener University School of Law and is a member of the New Jersey and Pennsylvania Bars.

**Lauren Agoratus** is the parent of a daughter with Asperger's syndrome and kidney disease. She serves as the New Jersey State and Region II (NJ, NY, VI, PR) Coordinator for Family Voices, a national advocacy group for children with special health care needs. Lauren is a member of the Association for Children of New Jersey's Health Month committee as well as their Medication Administration in Childcare Committee. She is the NJ Caregiver Community Action Network representative for the National Family Caregivers Association and was recently appointed by the Governor to serve on the State Interagency Coordinating Council for Early Intervention.

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### **Hinkle, Fingles & Prior, Attorneys at Law**

The attorneys at Hinkle, Fingles & Prior have more than 75 years of combined experience providing expert counsel and legal services to families of people with disabilities and seniors. The firm's attorneys have argued many of the precedent-setting cases affecting people with disabilities.

Hinkle, Fingles & Prior is a multi-state practice with offices in Lawrenceville, Cherry Hill, Florham Park, and Paramus, New Jersey and in Bala Cynwyd and Plymouth Meeting, Pennsylvania.

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# FAMILY VOICES NEW JERSEY

Family Voices aims to achieve family-centered care for all children and youth with special health care needs and/or disabilities.

Through our national network, we provide families tools to make informed decisions, advocate for improved public and private policies, build partnerships among professionals and families, and serve as a trusted resource on health care.

## National Office

Family Voices, Inc.

2340 Alamo SE, Suite 102

Albuquerque, NM 87106

505.872.4774 or 888.835.5669

Fax: 505.872.4780

<http://www.familyvoices.org/>

## In New Jersey

973.642.8100 x.110

[familyvoices@spannj.org](mailto:familyvoices@spannj.org)