

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 health care 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 health care 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:

- ① Learn everything you can about your child’s diagnosis. Once you know what you are dealing with, you will be empowered to make decisions.
- ② Connect with another family who also has a child with special needs.
- ③ 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.
- ④ Keep records of all telephone calls, physicians visits, insurance forms, and copies of any paperwork related to your child’s health care.
- ⑤ 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 available at 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 not available.

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 years of age), 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 for 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.

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 (3) and has at least a 33% delay in one developmental area 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

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 health care needs can have a case manager at no cost from SCHS from birth to age 21. A case manager 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 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.

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 FPL is \$10,830 for an individual).

For autism guidelines for early intervention, visit www.njeis.org.

ADVOCACY TIP:

If families have problems or concerns about EI services, they can reach the family support coordinator at their Regional Early Intervention Collaborative (REIC) at www.njeis.org, or the EI 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.

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

Pre-school programs for children with disabilities ages 3-5 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.

ADVOCACY TIP:

There is now a requirement for a parent special education group in each school district. Local parent groups can be found at 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 (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, see Special Education, next page).

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 school 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 school district must still provide the services your child needs even if you refuse your consent for Medicaid to cover them.

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 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 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

Autism guidelines for special education:

www.nj.gov/education/specialed/info/cosac_files/frame.htm

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

DDD is the primary funding source for services for adults with disabilities once special education services end – that is, once the child graduates at age 18 or ages out at age 21. DDD also provides some services to children under age 18.

Eligibility for DDD is defined 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 7 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 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 residential services may apply to individuals who have an income or to families when a child under the age of 18 receives residential services from DDD.

For children 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 to DDD.

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

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 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 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.

The Department of Children and Family Services (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.

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 children 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 \$500 and \$700 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 engage in any substantial gainful activity (SGA) of employment because of a disability. In 2009, SSA defined SGA in employment as one who grosses greater than \$980 per month. 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.

Special Needs Trusts (Lifespan)

Most parents want to leave assets to their children when they die; however, if a person with a significant disability receives assets, they may become ineligible for important federal and state services and benefits. The person will lose Medicaid and SSI and the assets may also be subject to recoupment by Medicaid or the state for services previously provided.

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 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 problems, it is recommended that parents establish a special needs trust (SNT). An SNT will make the assets available to protect and enrich the life of the person with a disability without jeopardizing benefits available from the government. An 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.

Special Needs Trusts are usually not funded until one or both parents die. An SNT can be funded through life insurance or estate assets distributed through one's Will. So long as the assets were never owned by 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, 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 person with a disability.

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

Guardianship (Age of majority, 18 years of age)

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 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 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 person 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 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 parents have secured guardianship for an adult child, they 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 decisions in the best interest of the person with a cognitive disability or mental illness 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 his or her guardian. It is important for parents to consider the value of maximizing their child's independence and ability to make decisions on his or her 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.

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 ensure that Medicaid benefits for the child with disabilities are not lost. A special needs trust is often needed.

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 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.

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.

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 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.

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

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:

- (a) necessary for the symptoms and diagnosis or treatment of the condition, illness or injury;
- (b) provided for the diagnosis or the direct care and treatment of the condition, illness, or injury;
- (c) in accordance with generally accepted medical practice;
- (d) the most appropriate level of medical care needed;
- (f) 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
- (g) furnished within the framework of generally accepted methods of medical management currently used in the United States.

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.

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 on the previous page*. 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 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, pre-vocational & day programming (including transportation); supported employment (including transportation); personal care assistant & training; integrated therapeutic network 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; 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 Resources section for contact information.)

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.

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: 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.

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 (See www.jhsph.edu) has developed a document on medical necessity that can assist insurers with defining medial necessity for persons with special health care needs.

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:

- ① 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 therapies, skilled nursing, dental care, out-of-network coverage, eye care and eyeglasses, and adaptive equipment.
- ② 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.
 - 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 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.

Appeals Procedures

Private, Self-Funded/Self-Insured, and State Health Benefits Plan Appeals

Generally speaking, all health insurance plans (that is, private, self-funded/self-insured, or state health benefits) provide three levels of appeal when a requested service is either denied, reduced, limited, or terminated or eligibility is terminated. These three levels typically consist of two internal appeals (one informal, followed by a formal appeal) and an external appeal before a neutral arbiter (that is, someone outside of the health plan). Depending on the type of plan, 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.

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

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 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.

Medicaid Managed Care System Appeals

As a Medicaid Managed Care beneficiary, in addition to the Fair Hearing appeal right described above, you can also choose to follow the three levels of appeal afforded private health plans.

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.

Resources

NJ Department of Banking & Insurance

P.O. Box 325
Trenton, NJ 08625-0325
800.446.7467
www.njdoibi.org

NJ Department of Health & Senior Services

P. O. Box 360
Trenton, NJ 08625-0360
800.328.3838
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

NJ Department of Education

Office of Special Education Programs

P.O. Box 500
Trenton, NJ 08625
609.292.4469
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>

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>

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.

800.772.1213

<http://www.socialsecurity.gov>

About the Authors

Lauren Agoratus is the parent of a daughter with autism and kidney disease and locally runs the Hamilton Township Parent Advisory Council for Special Education. She serves as the New Jersey State Coordinator for Family Voices, a national advocacy group for children with special health care needs, as well as the southern coordinator for NJ's Family-to-Family Health Information Center. 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, Caregivers of NJ Board member, and was previously appointed by the governor to serve on the State Interagency Coordinating Council for Early Intervention. Lauren is a volunteer with both NAMI (National Alliance for the Mentally Ill) NJ and Mercer County, as well as the National Community of Practice Collaborative School Behavioral Health/workgroup school mental health for youth with disabilities. She serves on the NY Mid-Atlantic Consortium for Genetic & Newborn Screening, LSNJ Medicaid workgroup, and several Medicaid HMO advisory committees. Lauren also serves on the NJ Chapter of AAP-Committee for Children with Disabilities, Healthy Childcare NJ Advisory Council, PCORE (Pediatric Council on Research and Education) newsletter, and PCORE EPIC Medical Home Pilot-Leadership Advisory Group. She is on the advisory councils for both Parent-to-Parent and the Family Support Center. Lauren is a volunteer on the editorial advisory board of the national Exceptional Parent magazine.

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

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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.

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Attorneys at Hinkle, Fingles & Prior have more than seventy 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 in New Jersey and Pennsylvania. They offer workshops and seminars to parent groups at no charge.

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