Understanding Your Health Care Insurance & Appeal Rights

A Guide for Parents of Children with Intellectual Disabilities

by S. Paul Prior, Esq.

Special Olympics New Jersey

About Special Olympics New Jersey

Special Olympics New Jersey is a non-profit organization that provides year-round athletic training and competition for children and adults with intellectual disabilities.

Special Olympics New Jersey is an statewide nonprofit organization dedicated to empowering individuals with intellectual disabilities to become physically fit, productive and respected members of society through sports training and competition. Special Olympics New Jersey offers children and adults with intellectual disabilities year-round training and competition in 22 Olympic-type summer and winter sports. There is no charge to participate in Special Olympics New Jersey.

Special Olympics currently serves more than 16,000 persons with intellectual disabilities in more than 450 communities in New Jersey.

About the Author:

S. Paul Prior has spent his legal career representing people with disabilities. As the younger brother of a man with autism, he has a life-long commitment to disability law. He has successfully argued leading cases before the New Jersey Supreme Court, Third Circuit Court of Appeals, as well as other state and federal courts. He holds a JD from Seton Hall University School of Law, and serves on the board of directors of 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.

Letter from the President of Special Olympics New Jersey

"While people with intellectual disabilities are offered more services in education and community placement, they are often overlooked and forgotten in the health care system."

- Health Care Status Needs of Individuals with Mental Retadation

In August, 2005, Special Olympics issued a report "Health Status Needs of Individuals with Mental Retardation," produced by researchers at Yale University's School of Medicine. The report confirmed what many had suspected:

"Individuals with MR (Intellectual Disabilities) are susceptible to many of the same health conditions as individuals in the general population, but may experience more access and quality of car e challenges than individuals without MR."*

Part of the difficulty experienced by children and adults with intellectual disabilities in accessing quality health care is the fact that most primary care providers avoid the role of care manager, leaving parents to coordinate the care for theri child.

To help improve the quality of life of individuals with intellectual disabilities, Special Olympics New Jersey has partnered with the Law Offices of Hinkle & Fingles to create this booklet to help families and care givers understand health care systems and insurance issues.

As a fellow parent of a child with intellectual disabilities, it is my hope that this booklet opens the window on health care advocacy for thousands of New Jersey caregivers and their loved ones.

Mark Edenzon, President
Special Olympics, New Jersey

** term adopted by Special Olympics in December 2005*

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The Health Care Status of Children and Adults with Intellectual Disabilities

Like those in the general population, adults with intellectual disabilities are at risk for chronic medical conditions, including cardiovascular disease, cancer, lung conditions and diabetes, and like those in the general population, the risk of disease among those with intellectual disabilities increases with age. But disease prevalence varies by severity of intellectual disability

Individuals with certain intellectual disabilities are at increased risk of cardiovascular disease, leukemia, respiratory disease and diabetes. Some may be more likely to have diseases that are less common among individuals in the general population, including atlantoaxial instability, congenital cardiac conditions and thyroid disease.

Although common childhood conditions such as ear infections and asthma are experienced by children with intellectual disabilities, little information exists about the prevalence or manifestations of these conditions in these children. Children with Down Syndrome and other conditions may experience increased prevalence of certain heart conditions, ocular conditions, dental conditions, muscular conditions and obesity.

According to the report commissioned by Special Olympics, individual medical care community preventive health services and health-related social supports are separate entities that are operated through different agencies. As a result, distinct sectors of care with different agendas, philosophies and funding streams have developed, leading to an overall fragmentation of health care for Americans.

In an effort to reduce costs and decrease fragmentation of services, health care financing in the United States has been organized into a wide range of managed care arrangements. Under managed care, a primary care

physician is the main point of entry. As 'gatekeeper,' this provider also serves as 'coordinator of care' between and within all sectors.

In addition, managed care plans use utilization management and practice guidelines to encourage users to access services through their primary care physician and not through the use of preventive care and specialty services. In this way, managed care has resulted in a decreased access to preventive and specialty health services among individuals in the general population. Under the care of health maintenance organizations (HMOs), individuals generally must endure longer waiting periods for care and have a limited use of specialists. As HMOs have increasingly gained responsibility in the behavioral care, concerns regarding the access to psychiatric and mental health services has increased

Like others, many individuals with intellectual disabilities who receive Medicaid have been transitioned into managed care plans This can be particularly detrimental because these individuals have unique health care needs that often require coordination by experienced providers.

10 Questions to Answer About Your Health Care

1. What type of coverage do you have?
2. Are you (or your child) entitled to other forms of coverage?
3. How can you coordinate benefits?
4. What is cover ed by (each of) your health car e insurance provider(s)?
5. Who can provide care?
6. How can you use specialists and out of network providers?
7. What is the referral process?
8. What are your financial responsibilities?
9. What is the appeals process?
10. What is the complaint process?

Overview

Health care insurance is a complex system. Understanding your health coverage is critical to securing the full range of health care services your child needs. You must not only know what type of coverage you have, you must learn about other programs through which your child could obtain coverage. The more you understand, the more you will be able to maximize your coverage and minimize your financial responsibility.

This booklet primarily explores the different ways to access care through health care service systems. You should also be aware that there are other sources that can provide primary or additional coverage for a particular therapy or service. For example, the Early Intervention Program (ages 0-3), the special education program from your local school district (ages 3-21), and state disability programs (all ages) are three different ways in which you might secure certain therapies or and services for your child.

Under most private insurance policies, there is a provision for continued dependent coverage for disabled dependent adults. Check your individual policy language to see what is required in order to extend your private dependent coverage of your disabled child. Typically, proof of disability is required.

Types of Health Care Insurance Coverage

There are several types of insurance coverage for health care services:

- private insurance (including group health plans);
- public assistance (Medicaid and Medicare);
- state-funded health benefits plans; and
- self-funded/-insured plans.

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

Private Insurance is provided by your employer or obtained on your own. Plans are governed by New Jersey law and are enforced, depending on the issue, by the New Jersey Departments of Health & Senior Services' Office of Managed Care and Banking & Insurance. Services and procedures covered under private plans vary widely. Some private plans may require referrals for special services, or may require you to use certain providers to receive coverage. Additional costs or co-payments may be required if you elect to use providers outside your plan's network.

Public Assistance Programs include Medicaid (New Jersey's State Plan, EPSDT Program, Managed Care, or 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, $500 or less in monthly income and no more than $2,000 in countable assets).

New Jersey's Medicaid State Plan - The New Jersey Division of Medical Assistance & Health Services (DMAHS) administers the state Medicaid program. Under the state plan, beneficiaries are entitled to a wide array of mandatory and optional services, including the following:

Mandatory

- In & Out-Patient Hospital Treatment
- Lab Test & X-rays
- EPSDT services
- Home Healthcare
- Physician services
- Nurse midwife
- Family assistance
- Nursing Home for over 21 years of age

Optional

- Residential Treatment Centers
- Optical appliances
- Dental
- Optometry
- Chiropractic
- Psychology
- Podiatrist
- Prosthetics & Orthodics
- Drugs during long-term care
- Durable Medical Equipment
- Hearing Aides
- Hospice
- Transportation
- Private Duty Nursing services
- Personal Care services
- Clinic services
- Therapies (speech, occupational, and physical)
- In-patient psychiatric care for under 21 & older than 65
- 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 Programs - When a child under age 18 is ineligible for Medicaid because of parental income or resources, the New Jersey Division of Developmental Disabilities (DDD) offers a Medicaid-funded waiver program that "waives" the consideration of parental income and resources. Known as the Community Care Waiver (CCW), this Waiver Program is for individuals with developmental disabilities who would otherwise require an institutional level of care but who can be served at home. The

CCW provides case management, respite care, habilitation (including pre-vocational, educational, and supported employment services), home and vehicle accessibility adaptations, personal emergency response systems, therapies, and other individual supports.

New Jersey also offers several other Medicaid-funded Waiver Programs that provide 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 & Senior Services (DOHSS).

Medicare. 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 individuals who are employees of the State. This coverage is similar to private employer-provided plans in that it is a fringe benefit of employment, with some fundamental differences. SHBP is a self-administered medical plans and is not subject to oversight by New Jersey's Departments of Health & Senior Services and Banking & Insurance, or the U.S. Department of Labor. SHBP has greater leniency in what they cover (or do not) and in what duration because they are not similarly subject to New Jersey's insurance laws. Plans offered to state employees vary in their coverage.

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. As with the SHBP, self-funded plans have greater latitude as to what they do and do not cover under the plan.

Coordination of Coverage

There are many reasons why the health needs of individuals with intellectual disabilities are not being met, among them: current systems of health care rely on an individual's ability to recognize the need for care, seek care when necessary and, coordinate the provision of care.

In addition to understanding what type of insurance coverage you have, it is important to understand who pays first for your health care, and it is your responsibility to tell your doctor and other providers.

It is important, therefore, to know that:

1. Medicaid is always the payer of last resort.
2. Typically, private insurance, state-funded health benefits plans, and self-funded / self-insured plans pay first. However, if you have Medicare in combination with other private insurance coverage, the payer of first resort is not always clear.

For example:

- If you are 65 years of age or older and are covered under a group health plan, Medicare pays first if your employer has less than 20 employees. If there are more than 20 employees, Medicare pays second.
- If you are covered under an employer retiree plan and are age 65 or older or disabled age 65 or older, Medicare pays first.
- If you are disabled and covered by a large group health plan with less than 100 employees, Medicare pays first. If there are more than 100 employees, Medicare pays second.
- If you are covered by Medicare because on your disability and also have Medicaid, Medicare pays first.
- Medicare pays second if your other coverage is a private plan.

Appeal Procedures

Disputes involving the denial of payment for a covered benefit, which is medically necessary; reduction, denial, or termination of a covered service (with or without notice); and denial or termination of eligibility for insurance or waivers are all issues that may give rise to an appeal. If you are covered by more than one form of insurance (e.g., private insurance and Medicaid or Medicare), coordinating benefits and billing can also give rise to disputes.

Private Health Insurance

Under New Jersey law, beneficiaries of private, managed care plans are afforded three levels of appeal - two internal appeals within the insurance plan and a third external review before an Independent Utilization Review Organization (IURO) contracted by the New Jersey Department of Health and Senior Services' Office of Managed Care (DOHSS/OMC.) The IURO decision is binding on all parties. The Department of Banking and Insurance (DOBI) reviews billing disputes and mental health parity issues. The stages of appeal are:

Stage 1 (Informal Internal Appeal): file your appeal as soon as possible, but generally no later than 10 - 15 days after you have received the decision that the covered benefit has been denied or will be reduced or terminated. The health plan has 5 business days (or within 72 hours in the case of an emergency) to respond, in writing.

Stage 2 (Formal Internal Appeal): file your appeal promptly (typically within 10-15 days), in writing, and send by Certified Mail, Return Receipt Requested. The health plan has 20 business days (or within 72 hours in the case of an emergency) to respond. If the stage 2 appeal is denied, the health plan must give you written notice detailing the reasons for denial and an explanation of your Stage 3 appeal rights.

Stage 3 (External Appeal): you must file this appeal within 30 days of the Stage 2 decision with DOHSS/OMC. Your appeal must include: a) your name and member identification number; b) the name and business address of the health plan; c) a brief description of the medical condition for which benefits were denied, reduced, or terminated; d) copies of the Stages 1 & 2 denials; e) written consent to obtain any necessary medical records from the health plan or physicians; f) a completed appeal application with the $25.00 fee ($2.00 for hardship cases); and g) a copy of the "summary of insurance coverage" from your member handbook. DOHSS/OMC will assign the appeal to an IURO, which will review the appeal and issue a decision within 30 days. The IURO decision 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 (DOBI) or Department of Health & Senior Services (DOHSS) to complain.

New Jersey State Medicaid Plan

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 any time there is a proposed change to your Medicaid benefits or services. The written notice must:

- be timely (generally, at least 10 days before the proposed termination or reduction of services);
- explain how to obtain a Fair Hearing;
- explain how and which benefits will continue pending the outcome of the Fair Hearing; and
- explain that you can be represented by legal counsel, or have another person at the Fair Hearing to speak on your behalf.

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. 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 Managed Care Grievances and Appeals

Medicare Managed Care complaints are handled differently, depending on the nature o 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.

Step 1. If a health service or payment for a health services is denied, reduced, or terminated, you must be informed of such in writing within 14 days of the MCO receiving the request for the service or payment. You may choose to file for reconsideration, which must be in writing, within 60 calendar days of the date of the managed care plan's written notice denying, reducing, or limiting the health service, or payment for the health service. Reconsideration requests may be filed either with the MCO or the local Social Security Office. The MCO must respond within 30 days for decisions related to health services, and within 60 days for decisions related to payment. If the decision is not favorable, the MCO must inform you of such in writing, and then automatically proceed to a Step 2 (Independent review).

Step 2 - Independent Organization Review. The independent organization will review the reconsideration (either within 30 days for health services, or the expedited 72-hour time frame). Their decision must be in writing and mailed to you, including the reasons for the decision. If the decision is not favorable, you may proceed to Stage 3 if the dispute is over $100.00.

Step 3 - Administrative Law External Review. You must file a request for hearing within 60 days of the date of the decision from Stage 2.

Step 4 - Departmental Appeals Board Review is a review before an Appeals Board, following an unfavorable decision at Stage 3, where dispute is more than $1,000.

Step 5 - Final Level of Review is a 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.

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 can be appealed to the Of fice of Administrative Law (OAL).

Self-Funded / Self-Insured Plans Appeals

Self-funded plans have significant latitude as to what they do and do not cover under the plan. Appeals under such plans must be filed with the U.S. Department of Labor. Because there is no internal appeals process or state agency involved with these appeals, it is critical to examine the cover of your member handbook to determine whether you have this type of plan.

Publicly-Funded Programs For the Lifespan of the Individual with a Disability

Birth through age 3: Early Intervention Services

The Early Intervention System (EIS), under the Division of Family Health Services, implements New Jersey's statewide system of services for infants and toddlers, birth to age three, with developmental delays or disabilities, and their families. EIS is funded in part by the New Jersey Department of Health and Senior Services, with state and federal funds.

In New Jersey, a child is considered eligible for early intervention services 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 of the developmental areas:

- Physical, including gross motor, fine motor, and sensory (vision and hearing);
- Cognitive;
- Communication;
- Social or emotional; or
- Adaptive.

Public and private agencies serve as providers. Following an evaluation and assessment, an Individualized Family Service Plan (IFSP) is developed to describe the services that are needed by the child and family and how they will be implemented. The need for discipline-specific therapy is determined by an evaluation or assessment by a therapist from the area of concern. The frequency and intensity of the therapy are determined by the entire IFSP 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/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.

Ages 3-21: Special Education Services

Children between the ages of 3 and 21 with disabilities severe enough to negatively affect learning are entitled to special education services at no cost to parents. These services are federally mandated in all states. Special education in New Jersey is the responsibility of local school districts, with oversight provided by the New Jersey Department of Education.

School districts are responsible for identifying, evaluating, and then classifying children with disabilities as eligible for special education and related services. State regulations set out timelines 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 districts must annually develop a written Individualized Education Program (IEP) that outlines the services to be provided with measurable goals. For some children, the IEP might involve classroom modification, or individual instruction or therapy. Other children might require placement in a specialized class or placement in a private school which 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.

Children may be eligible for 'related services' as part of their IEP. Related services may include speech therapy, occupational therapy, physical therapy, and school-based nursing services.

Schools must document a child's 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.

Ages 18+: Adult Services

The primary funding source for services for adults with disabilities is the New Jersey Division of Developmental Disabilities (DDD). Under certain circumstances, DDD also provides services to individuals 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 6 major areas of life activity.

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

Services from DDD can include case management services, adult day programs, residential placement, vocational services, and family support services (including, 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).

Services are offered at no charge 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.

Other state agencies such as the New Jersey Divisions of Vocational Rehabilitation Services (DVRS) and Medical Assistance & Health Services (DMAHS) offer different services.

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 & 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.

Resources

New Jersey Department of Banking
and Insurance,
Division of Insurance
P.O. Box 325
Trenton, NJ 08625-0325
1-800-446-7467
www.njdobi.org/

New Jersey Department of Health
and Senior Services (DHS),
Division of Family Health Services
P. O. Box 360
Trenton, NJ 08625-0360
1-800-328-3838
www.state.nj.us/health/

New Jersey Department of Human Services
Division of Developmental Disabilities (DDD)
P.O. Box 725
Trenton, NJ 08625-0725
1-800-832-9137
http://www.state.nj.us/humanservices/ddd/
index.html

New Jersey Department of Labor & Workforce
Development
Division of Disability Services (DDS)
PO Box 382
Trenton, NJ 08625-0382
1-800-772-1213
http://www.state.nj.us/labor/dds/
ddsforms.html

Division of Vocational
Rehabilitation Services (DVRS)
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 (DOE)
Office of Special Education Programs
PO Box 500
Trenton, NJ 08625
(609) 292-4469
www.state.nj.us/njded

New Jersey Division of Medical Assistance
and Health Services (DMAHS)
Quakerbridge Plaza
P.O. Box 712
Trenton, NJ 08625-0712
1-800-356-1561
http://www.state.nj.us/humanservices/dmahs/

State Health Benefits Coordination
New Jersey 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

New Jersey Office of Administrative Law
P.O. Box 049
Trenton, NJ 08625-0049
(609) 588-6501
http://www.state.nj.us/oal/general.html

New Jersey Department of Health and Senior
Services
Early Intervention System (EIS)
PO Box 360
Trenton, NJ 08625-0360
http://www.njeis.org
http://nj.gov/health/fsh/eis/index.shtml

The Social Security Administration
http://www.socialsecurity.gov/disability/
call 1-800-772-1213 to apply.

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