THE MANAGED HEALTH CARE CURRICULUM:

Supporting People with Disabilities to Utilize Managed Health Care

LEARNING HOW TO USE MANAGED HEALTH CARE

WORKBOOK

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TABLE OF CONTENTS

WORKBOOK
LEARNING HOW TO USE MANAGED HEALTH CARE

INTRODUCTION

During this training, you will have the opportunity to:

- Get information about managed health care;
- Learn the meaning of the words used in managed health care;
- Learn how to use a health care plan for the people you support;
- Learn how people with disabilities will choose a health plan;
- Discover how Medicaid Managed Health Care will work in NJ;
- Learn how to work within managed health care;
- Practice what to say in situations you may have to deal with in managed care.

In this training – you will have the opportunity to learn more about managed health care and how to get the best health care you can for the people you support. We'll talk about managed health care and people with disabilities, but if ***you*** have health care insurance through a managed care company, most of the information in the training will also apply to you.

Today's training is divided into 4 sections:

- Understanding Managed Health Care
- How Managed Health Care Works for People with Disabilities in NJ
- Choosing a Health Plan and Primary Care Provider
- Problem Solving in Managed Health Care

1.0 UNDERSTANDING MANAGED HEALTH CARE

1.1 What is Managed Health Care?

In a managed health care system, a person receives their health care through health plans.

The most common type of health plan is called an HMO, for Health Maintenance Organization. We'll be talking about HMOs today. It is also important for you to know that there are different types of managed health care. They are not all exactly the same.

We'll call all health plans "plans". When someone receives his/her health care through a plan, he/she becomes a member of the health plan. The plans have relationships with different health providers, called a network. Each person, who is a member of the plan, chooses a Primary Care Provider (PCP), who is his or her regular doctor. The PCP will coordinate all of the member's health care and provide referrals to specialists when needed. Health plans provide care for when a person is sick and also if they need to go to the hospital. Health plans also want to keep people healthy, so they like people to get checkups, physicals, and immunizations. Some plans even have programs to help people stay healthy, for example, programs to stop smoking or lose weight.

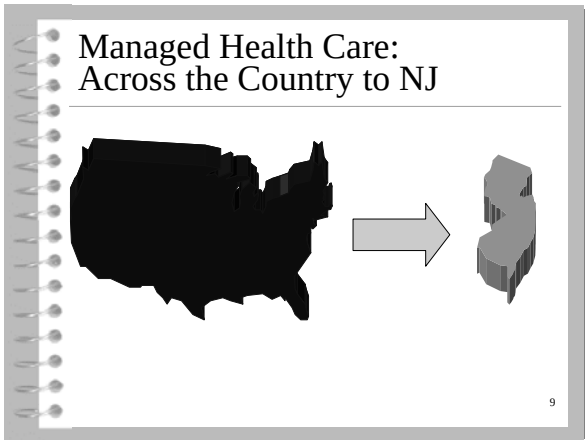
We are now going to talk about the change to managed health care and how managed health care is different from the way people with disabilities have been getting their health care.

1.2 The Change to Managed Health Care

Managed care is a change in how people with disabilities get their health care. It's a change for you, people with disabilities, your community provider agency, Medicaid, doctors, and the health plans.

Managed health care can:

- Give people better access to doctors who accept Medicaid
- Coordinate care between a Primary Care Provider and specialists, such as neurologists



Managed health care is the way people are getting their health care all across the country. Most people who have health insurance through their job have managed health care. Currently, about 60 million people, one quarter of the US population, have managed health care.

Managed health care is now also used to provide health care to children without health insurance, for some people who get Medicare, and for many people who receive Medicaid. Across the country, most people who get Medicaid are required to enroll in managed health care.

Why? States are moving to managed health care for 2 main reasons:

1) To coordinate and improve the quality of care for people who have Medicaid.

2) To save money.

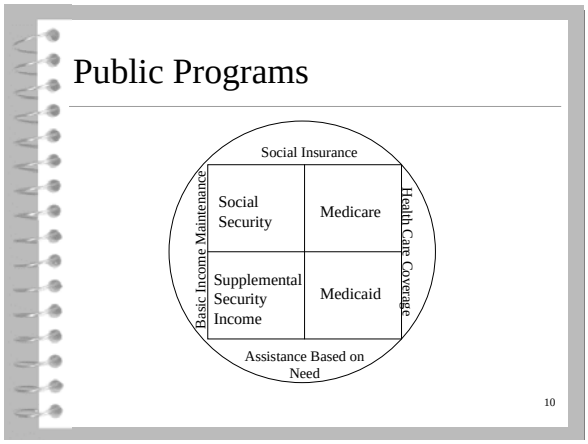
We'll talk more about this when we discuss the differences between the way people get their health care now and managed health care.

When a state requires people who receive Medicaid to use managed health care, it's called Mandatory Medicaid Managed Care. Most states have already required people who receive Temporary Assistance to Needy Families (TANF) and Medicaid to enroll in managed health care.

Many states, including New Jersey, are starting to require people with disabilities who receive Supplemental Security Income (SSI) and Medicaid to enroll in managed health care. This includes people in a broad group which Medicaid calls the Aged, Blind and Disabled category, including individuals with developmental disabilities.

This means that all people with disabilities who receive Medicaid will need to enroll in health plans. There are some exceptions, such as people who receive both Medicare and Medicaid. New Jersey will not require people who are "dually eligible" with Medicare and Medicaid to enroll until the second year of the program. People who are dually eligible may voluntarily enroll in managed care. Details for this enrollment are not yet finalized. We'll talk about other exceptions to enrollment later.

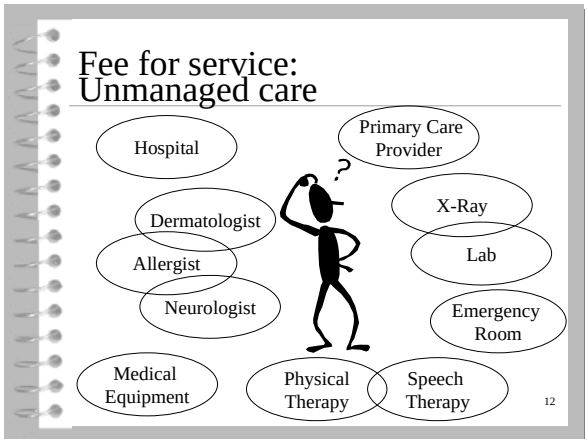
As of this time, it is expected that enrollment for the SSI population in New Jersey will begin in March 2000. Before enrollment, individuals will receive a letter from Medicaid explaining the process. We will talk more about enrollment when we talk about NJ's program.



1.3 Managed Health Care: What Is It and How Is It Different?

You need to know how health plans work, in order to get the best health care you can for yourself and for the people you support.

The first picture shows "Fee for Service."



With this way of getting health care, a person could go to any doctor or hospital that accepted Medicaid. Often it was difficult for people who received Medicaid, especially people with disabilities, to find health providers who would treat them. This has been an issue particularly with dentists and mental health providers. Also, health care under fee-for-service usually was not coordinated, since people could go directly to many types of health providers.

Medicaid Managed Care works differently than fee-for-service Medicaid. Managed Health Care is different because it is more structured. There are also many benefits to Managed Health Care because it focuses on prevention of illness.

Managed Health Care is a way of providing health care and paying for health care.

We will focus on 7 important ideas about using managed health care.

1) Primary Care Provider
2) Network
3) Referrals/specialists
4) 24 hour coverage phone number
5) Emergencies
6) Medicaid card and health plan card
7) Payment for health services: Capitation

Primary Care Provider (PCP)

When a person chooses a plan, they also choose a Primary Care Provider, a PCP. Usually a PCP is a doctor.

The doctor could be a:

- Family Practice Physician – children and adults (life span)
- Internist - adults
- Pediatrician - children

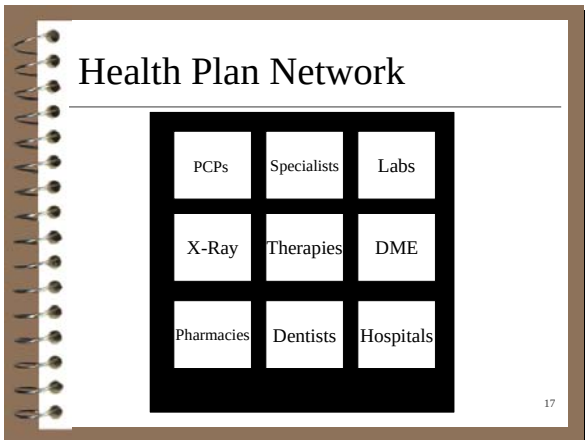
In Medicaid in New Jersey, a person could also choose a nurse practitioner or specialist to be their Primary Care Provider. This health provider is a person's "regular doctor" or nurse.

The PCP could be his/her current health provider. In Medicaid in New Jersey, if a person is a current fee-for-service patient of a provider in a health plan that he/she chooses and selects that provider to be his/her PCP, the PCP must accept him/her as a patient (even if they don't have room for new patients).

The PCP keeps track of all of a person's health care. This is the doctor to call when you or someone you support gets sick or hurt, needs a checkup, immunizations, medical advice, prescription drugs, or prescriptions for medical equipment. Each person has his or her own primary care provider. The PCP has an important role in referrals and coordinating care.

The PCP is a *partner.* This idea is central in managed health care.

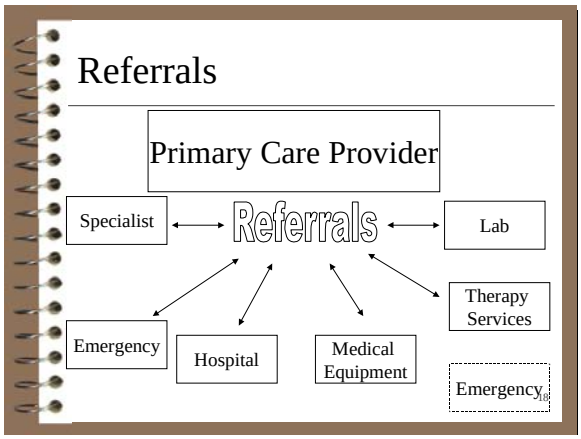
Network



The next picture shows a network. Under managed health care, a person joins a health plan. The plan has relationships with doctors, hospitals, and pharmacies to provide health care to members of the health plan. This is called a network.

When someone joins the health plan, he/she will get a member handbook, membership card, and directory of all the health providers who are part of the plan's network. The person needs to use the plan's network for the plan to pay for the person's health care unless their Primary Care Provider refers them to an out-of -network provider. If a person tries to get care outside of the plan without permission, he/she will get a bill for the visit.

Referrals



In managed health care, people need permission from their PCP to see a specialist, such as a neurologist. This is called a referral. The Primary Care Provider may give the person a written referral form or send it by fax or computer. If given a written form, the person needs to take this form with them to the neurologist.

Referrals are needed for 3 reasons:

- Access
- Coordination of care
- Financial reasons

For example, a person must go to a lab in network so that the lab will accept them and communicate back and forth with their doctor.

In many states, including Medicaid in New Jersey, people can go directly to certain specialists, such as Obstetricians/Gynecologists. Some states, including Medicaid in New Jersey, also allow people to use a specialist as their PCP if it is medically necessary.

The Primary Care Provider may also be able to give a standing referral. This will let the person see a specialist for a certain number of visits or length of time.

24 hour coverage number

Members of an HMO can call the Primary Care Provider or health plan for help 24 hours a day. If a person gets sick in the middle of the night or if they cannot reach the PCP after hours (usually after 5pm and weekends), they should call the plan's 24-hour number.

This number should be on their health plan member identification card. The 24-hour number staff will help to figure out where you can get care. Be sure to check with the PCP and health plan about what to do if there is a problem after hours. The PCP will most likely have an answering service with a live person after hours.

The 24-hour number can also be used to make complaints to the plan. This number might be referred to as their "customer service" number. Some plans also have nurses who can answer medical questions 24 hours a day.

Emergencies

Managed health care plans have rules and procedures to follow for emergencies. Health plans don't want people to use the Emergency Room unless they have a true medical emergency.

In general, emergency rooms aren't the best places for people with disabilities to be treated because the doctors there won't know the person. There also will be no follow up treatment to their emergency room visit. Emergency rooms are a very expensive way of providing care.

New Jersey has adopted the Prudent Layperson Standard: if a typical person without medical training would think it's an emergency, go to the emergency room.

The exact definition is as follows:

> ***Emergency medical condition***: a medical condition which manifests itself by acute symptoms of sufficient severity, (including severe pain) such that a prudent layperson, who possesses an average knowledge of medicine and health, could reasonably expect the absence of immediate medical attention to result in:
>
> - Placing the health of the individual (or, with respect to a pregnant woman, the health of the woman or her unborn child) in serious jeopardy;
> - Serious impairment to such person's bodily functions;
> - Serious dysfunction of any bodily organ or part of such person; or
> - Serious disfigurement of such person.

⇨ Some common examples of emergency situations are as follows:

- Excessive bleeding which you are unable to control.
- Accidents involving severe injury.
- Breathing difficulties, such as obstruction/choking, no breathing.
- Circulatory system difficulties, such as heart attack or no pulse.
- Loss of consciousness unrelated to predictable seizure activity.
- Behavior which is a danger to themselves or others and is not controllable.

When a person joins a plan, be sure to check with the PCP and the health plan about emergencies and read the member handbook. Ask the question: "What do I do in case of a problem after hours?" "What do I do in case of emergency?"

✎ In addition to the rules of the managed health care plan, you also need to follow the procedures of your community provider agency. Check with your supervisor about what to do in an emergency. You're responsible for knowing the policies of your agency.

Medicaid Letter/Health Plan Card

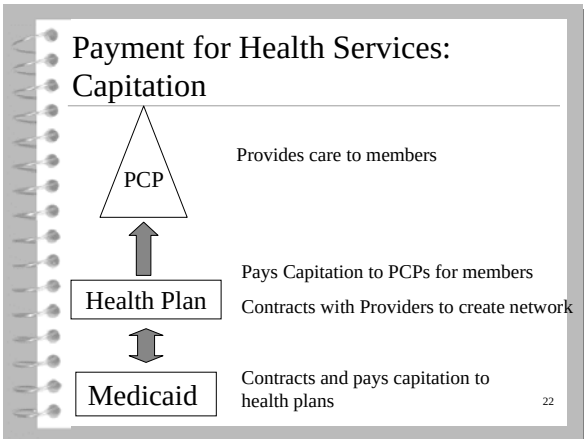
When a person enrolls in a health plan, he/she will get a health plan membership identification card. This card will have the person's name and the name of their Primary Care Provider on it. The card will also have the plan's 24 hour number on it and customer service information.

People should always bring their health plan card ***and*** their Medicaid eligibility letter, which they get each month, as well as Medicare or other medical insurance cards when they go to a health care appointment or the emergency room. Since Medicaid eligibility is updated monthly, it is very important to always have the current eligibility letter. Some plans will also have a separate card for prescriptions, while other plans will have the same card for both health care and prescriptions.

It's important to have a place where the person's Medicaid letter and health plan cards are ***always*** located. They should be put back in the same place after every health care appointment. Make a photocopy of the letter and cards to keep in a safe place.

People with disabilities may still use their Medicaid eligibility letter to get services that are not provided by the HMO. In New Jersey, people will still need their Medicaid eligibility letter for Personal Assistance Services, rehabilitation therapies, and some other examples we'll talk about later.

Payment for Health Services: Capitation



One big difference between fee-for-service health care and managed health care is how doctors and other health providers get paid. Doctors get paid for every service they provide in fee-for-service. The more services they provide e. g. doctor's visits, the more they get paid.

In managed health care, the plan negotiates how much they will pay to the providers (e. g. doctors). Plans pay providers a set amount every month for each of their patients. This is called capitation. Providers are paid the same amount no matter how many times they see a patient.

In managed health care, the payer pays the capitation to the health plan. In New Jersey's Medicaid Managed Care Program, Medicaid pays the capitation to the health plan. Capitation rates are determined according to a formula. It is very complicated, but the important thing to know is that the rates are not the same for all groups. There are different rates for people who have SSI and are disabled in New Jersey.

Because managed health care is focused on prevention, health plans and their doctors try to keep people as healthy as they can. Preventing an illness or a problem from getting worse is always in the best interest of the individual and the health plan.

The Managed Health Care Challenge

Round 1 Questions

1. Health Plans pay doctors the same amount of money each month for every patient. This is called _____.

2. The doctor you go to when you are sick or need a prescription is called a _____.

3. The way we used to get health care is called _____.

4. A central idea in managed health care is that your Primary Care provider (PCP) is a _____.

5. You can usually find the 24-hour phone number on the back of the _____.

6. Health Plans have professional relationships with doctors, pharmacies, and hospitals, this is called a _____.

Round 2 Questions

1. Members of a health plan usually have to get a _____ form from their PCP to see a specialist.

2. When a person with a disability goes to a health care appointment he/she must always bring their _____card and their Medicaid eligibility letter with them.

3. Health plans don't want people to use the Emergency Room unless they have a true _____.

4. In New Jersey a person can choose a physician, a nurse practitioner, or a _____to be their PCP.

5. A _____ will let a person see a specialist for a number of visits.

6. In order for the health plan to pay for the doctor's visit the member must use a provider in the plan's _____.

2.0 HOW MANAGED HEALTH CARE WORKS FOR PEOPLE WITH DISABILITIES IN NEW JERSEY

2.1 Managed Health Care and People with Disabilities

Depending on how their health care is paid for, people may have different rights under managed health care. For people who have Medicaid, the state Medicaid agency pays the health plans.

The state Medicaid agency, the Division of Medical Assistance and Health Services, has a contract with each of the HMOs to provide health care for people in Medicaid. The contract has the list of benefits that have to be provided - the benefit package. In NJ, the contract also has special rules that HMOs have to follow for people who have Medicaid. There are also rules about what plans have to do for people with disabilities. These are what we call "Medicaid Protections".

This Medicaid contract was developed with a lot of input and hard work from advocates, people with disabilities, and family members. They worked with Medicaid to make sure that people with disabilities receive the best care they can in managed health care.

We're now going to go through the most important items for people with disabilities in managed health care in New Jersey.

Enrollment

The process where people choose a health plan and a Primary Care Provider is called enrollment. Only an authorized person – the person with disabilities, the parent or guardian, or someone who has power of attorney can make the decisions for enrollment. Individuals need to enroll in order to be a member of a health plan and to begin receiving health services.

Health Benefits Coordinator Agency

In New Jersey and most states, there is an agency to help people who receive Medicaid to enroll in health plans. Currently the Health Benefits Coordinator agency is Maximus (the agency may stay the same or change in the future but there will continue to be a Health Benefits Coordinator).

This agency is independent from the health plans. They will receive and process enrollment forms, provide assistance locating PCPs, and answer questions about enrollment. They will also help if a person needs to change his/her health plan or PCP. The Health Benefits Coordinator agency provides some other services as well, such as helping if there is a problem with a plan.

Exemption

Some people with disabilities who receive Medicaid in NJ may not be required to enroll in managed care.

Currently, the only people with disabilities who are not required to enroll in managed care are:

- People who live in developmental centers (institutions)
- Individuals in out-of-state placements
- Individuals in certain Home and Community Based Waiver programs
- Individuals already enrolled in a Medicare HMO that is not part of the Medicaid Managed Care program.

In addition, individuals who have Medicaid and Medicare (dually eligible) will not be required to enroll in the first year of the program.

Anyone else who wants to be exempt must file for an exemption.

Exemptions are processed by the Health Benefits Coordinator agency and forwarded to Medicaid. If exemptions are approved, the person would be able to continue receiving their health care services on a fee-for-service basis.

> ✎If the person with disabilities you support wants to be exempt, find out what steps he/she would have to take to get an exemption.

Benefit Package

The list of covered health services that will be paid for by the health plan are called benefits. The benefits for people who receive Medicaid in New Jersey is in the Medicaid contract.

The major covered benefits are:

- Primary care and specialist visits
- Hospital visits
- Emergency room
- Labs
- Pharmacy
- Durable medical equipment
- Dental care
- Mental health care for people who are clients of the Division of Developmental Disabilities (DDD)*

* For people who are not clients of DDD, mental health care will remain fee-for-service in Medicaid.

It is important to know that there are some services not included in the capitation that will still be paid for, but will not be provided by the health plan. Some examples of these are mental health care for people who aren't clients of DDD, personal care assistant services, and rehabilitation therapies such as physical therapy, occupational therapy, and speech. These services will still be "fee-for-service". That's one reason why the person still needs to have his/her Medicaid eligibility letter.

Find out the list of covered services by reading the member handbook. The Health Benefit Coordinator Agency will also have informational brochures which list the benefits.

The following items are parts of the benefit package in New Jersey that are very important for people with disabilities.

Care management

Some states provide care coordination services for people with chronic diseases, such as cancer or diabetes, and other disabilities under Medicaid Managed Care. In New Jersey, it's called Care Management.

In NJ, Care Managers may be social workers, nurses, or other professionals employed by the health plan. As part of the transition to managed health care, a Complex Needs Assessment will be done to determine the level of a person's care needs.

The role of the Care Manager is to help people with disabilities or special health care needs to get the health services they need from the HMO.

They will:

- Develop Individual Health Care Plans (IHCP)
- Provide assistance in referrals
- Coordinate between medical care and other supports

If a person with disabilities has a problem with the health plan, the Care Manager should be called.

Specialty services in a plan

Some people have special health care needs because of their disability. Some plans may have specialty services and/or clinics for specific disabilities, like Spina Bifida, Down Syndrome, Cerebral Palsy, or Spinal Cord Injury.

✎If it's important to the person's health that he/she be seen in a specialty clinic, find out which plans have specialty services in their network, or if they will refer someone out-of-network for these services.

Lab or x-ray services

Lab tests, like blood or urine tests, or x-rays, may be done at the doctor's office or at a separate location.

✎Check with the health plan about where lab services and x-rays are provided. Under managed care, all labs may not be included in the plan's network.

Sedation

A drug that relaxes the person or helps them sleep while a medical or dental procedure is being done is called sedation. A small number of people with developmental disabilities need sedation for routine medical procedures such as Pelvic exams, Pap smears, Prostate exams, and Dental care. Sedation needs to be specially arranged. Other means of helping the person to be able to undergo routine medical procedures should be tried whenever possible before sedation is utilized. Sedation can only be prescribed by a physician.

✎If needed, find out how sedation is arranged and coordinated. Try to work with the PCP and/or Care Manager to coordinate different procedures to be done at the same time, such as dental and gynecological exams.

Durable Medical Equipment (DME)

Items kept for a long time that help the person to stay healthy or be more independent are described as durable medical equipment. Usually, a health provider must prescribe DME. Examples of DME are wheelchairs, ventilators, and assistive communication devices.

✎Check out what the plan's rules are for getting durable medical equipment and for getting it maintained. Find out who the plan's DME providers are.

Medical Necessity

Plans use the definition of medical necessity to decide whether or not they will cover or pay for a service. For people with disabilities who have Medicaid, the definition of medical necessity in the state's Medicaid contract with the health plan is the one that plans have to follow. It is very important, since plans could deny services according to this definition. It could also help you in advocating for services.

The term is used to describe medical, surgical, or other health that are required to:

- diagnose or prevent an illness, injury or condition;
- treat an illness, injury or condition;
- keep a condition from getting worse, to lessen its pain or severity, or help it get better;
- restore lost skills or provide rehabilitation because they are medically necessary.

On the following page is New Jersey's definition of medical necessity for people who receive Medicaid. Hold onto it with your other materials, as you may need to use it if you encounter a problem.

This is New Jersey's Definition of Medical Necessity:

- Services or supplies necessary to prevent, diagnose, correct, prevent the worsening of, alleviate, ameliorate, or cure a physical or mental illness or condition;
- To maintain health;
- To prevent the onset of an illness, condition, or disability;
- To prevent or treat a condition that endangers life or causes suffering or pain or results in illness or infirmity;
- To prevent the deterioration of a condition; to promote the development or maintenance of maximal functioning capacity in performing daily activities, taking into account both the functional capacities that are appropriate for individuals of the same age;
- To prevent or treat a condition that threatens to cause or aggravate a handicap or cause physical deformity or malfunction, and there is no other equally effective, more conservative, or substantially less costly course of treatment available or suitable for the enrollee.

The services provided, as well as the type of provider and setting, must be:

- reflective of the level of services that can be safely provided, must be consistent with the diagnosis of the condition and appropriate to the specific medical needs of the enrollee and not solely for the convenience of the enrollee or provider of service and in accordance with standards of good medical practice and generally recognized by the medical scientific community as effective.
- Course of treatment may include mere observation or, where appropriate no treatment at all.
- Experimental services or services generally regarded by the medical profession as unacceptable treatment are not medically necessary for the purposes of this contract.

In the case of pediatric enrollees, this definition shall apply with the additional criteria that:

- these services, including those found to be needed by a child as a result of a comprehensive screening visit or an inter-periodic encounter whether or not they are ordinarily covered services for all other Medicaid enrollees, are appropriate for the age and the health status of the individual and that the service will aid the overall physical and mental growth and development of the individual and the service will assist in achieving or maintaining functional capacity.

- Medical necessity decisions for children should be based on peer-reviewed publications, expert pediatric and psychiatric medical opinion, and medical community acceptance.

 For people who don't have Medicaid, each plan's definition of medical necessity is different. There should be a definition of medical necessity in their member handbook.

♿ Accessibility

The Americans with Disabilities Act (ADA) requires that all health plans, and the doctors or other providers that are part of the plans, provide services in an accessible manner. This means that the office either needs to be accessible or the doctors need to provide health services to the person in an accessible location.

✎If necessary, ask the health plans and doctors' offices about:

- **Physical accessibility**
  Is the office accessible to someone who uses a wheelchair? If not, will services be provided in an accessible location? Are the exam rooms accessible? Are the exam tables accessible? Is there a lift and where is it located?
- **Deaf/hard of hearing**
  Do they use a TDD or phone relay service? How are sign language interpreters arranged?
- **Distance**
  Is there a limit for how far people have to travel to see a health provider?
- **Language**
  What languages do the doctors or health providers speak? How are foreign language interpreters arranged?
- **Alternate formats**
  Are materials available in large print, Braille, audiotape, computer disks, or foreign language? How are these made available?

Transportation

Anything from buses, vans, and taxis to stretcher cars and ambulances may be called transportation.

✎If transportation won't be provided through the residential agency, find out whether they can get transportation through Medicaid or the HMO. If a person can travel independently, find out if the doctor they like is near a public transportation route.

Case Study

Situation 1

Tamara Parks appears to be depressed. Her mood swings from very happy to very down. She has not been eating as she normally does. She appears disinterested, even in the activities she usually enjoys. She has been late for work several times in the past few weeks, which is unusual for her. She still gets together with Jake, her boyfriend, but they usually stay in her apartment.

Situation 2

Mike Choi has been on the same anti-seizure medication for two years and his seizures have been well controlled. In the past three months he has had an increase in the number and severity of seizures. He has seen his PCP three times and the PCP has increased his medication. He appears to be drowsy and the seizures have not diminished. You have asked twice for a referral to a neurologist. The PCP wants to wait a little longer to see if the increased medication works.

Situation 3

Kyle Jefferson has been followed by his pediatrician, Dr. Issacs, for 5 years. Kyle and his parents are very comfortable with her and trust her. They have also been using the Medical Center Spina Bifida Clinic since Kyle was born. Communication between Dr. Issacs and the Clinic has been good and this has helped Kyle and his family deal with some difficult health issues. As Kyle has grown he has needed changes to the equipment he uses. Mr. Jefferson is in the process of changing jobs and this will mean a change in health care insurance. The Jeffersons have asked CHS to help them to figure this out.

Situation 4

Nate Whitman has Dr. Jones as his PCP. You have accompanied Nate to three medical appointments. During the initial appointment Dr. Jones asked you most of the questions. You did a good job assisting Nate to answer them and you thought that Dr. Jones was beginning to understand that Nate knew about his health and could answer his questions. At the second appointment the situation was the same. Following the appointment you called Dr. Jones office and communicated your concern to the nurse, she said she would make sure that Dr. Jones knew that he should talk directly to Nate. At the third appointment there was a new medical concern raised and Dr. Jones told you that he did not have time to explain things to Nate.

Situation 5

Janet Miller is involved in the agency's community participation program so she is out of her home for a few hours every day. She shows enthusiasm for these activities and her parents enjoy meeting her at places in the community. Janet has a heart problem that needs to be followed on a regular basis. She has been going to the same cardiologist that her Father sees, Dr. Woods. Dr. Woods knows Janet and relates to her well. Dr. Woods is not participating in the same plan as Janet's Primary Care Provider, Dr. Rose. Because of Dr. Rose's knowledge of Janet and his experience in treating her for pneumonia, the Millers are reluctant to make a change.

ADDITIONAL INFORMATION ON SOME PEOPLE WHO RECEIVE SERVICES THROUGH THIS AGENCY (OPTIONAL)

Tamara Parks lives with another woman in an apartment that is part of the CSH independent living program. Staff are with her for a specified number of hours each day. She has a job at a local grocery store and she has a relationship with a young man who lives about 1/2 mile from her. She has lived in several different CSH settings over the past 10 years.

Mike Choi lives in one of the CSH group homes, 4 other men live there with him. Mike's family lives in another state and they aren't able to visit very often. Mike is basically a quiet person. He is a good friend to another gentleman who lives with him. He most enjoys spending time with staff both talking to them and listening to their conversations. Mike has a seizure disorder that has been very well controlled by medication for several years.

Nate Whitman is an elderly gentleman. He has lived in a CSH group home for three years. Before that he lived at a large state facility for most of his life. As he has aged he has started to have some health concerns. He has trouble sleeping, the stairs are more difficult for him to climb, his appetite seems to have changed and he has difficulty hearing. He goes out to a senior center three days a week but often refuses to go out with his housemates if walking is involved. Nate has a lot to say and enjoys talking but people who don't know him well may have difficulty understanding him.

The Jeffersons participate in one of the CSH family support groups. Their son, Kyle goes on some of the outings the group plans for children. Kyle is 9 years old; he has spina bifida and uses a wheelchair and sometimes crutches. He attends the neighborhood elementary school and participates in other activities including scouting, swimming and a computer club. Kyle has had the same pediatrician since he was 4 years old and he has been seen at the Medical Center Spina Bifida Clinic since birth.

Hal and Ruth Miller are part of the CSH extended family. Their daughter Janet now lives in a CSH group home. Hal and Ruth live about 3 miles from the group home and they go with Janet to most medical appointments. The Millers were very active in getting CSH open when the agency first started. Janet lived at home with them until 5 years ago. Janet is blind and she uses gestures and sounds to communicate. She also has a mental disability. Janet has been hospitalized several times in the past 8 years for pneumonia.

Michelle Adams has lived in her apartment with two other women for 4 years. One of the staff has been working with her for the entire time. The other staff have been with the agency for less than one year. Sometimes staff from other homes fill in at Michelle's apartment. Michelle communicates using some words and gestures. She understands most of what is said to her and can respond to questions. Michelle started a new job about two weeks ago and has been very enthusiastic about going.

ADDITIONAL INFORMATION ON THE COMMUNITY SERVICE AGENCY (OPTIONAL)

Community Service Homes (CSH) is a not-for-profit provider agency that operates residential and employment services for people with disabilities who live in New Jersey. The agency offers several residential living options including group homes, apartments and independent living. All of the employment services are community based and include supported employment.

About 4 years ago CSH also started some programs for families with young children who have developmental disabilities. Through outreach and support groups the agency is assisting about 20 families.

CSH is responsible for overseeing the health care for everyone who lives in one of their residential settings. Their direct support staff and management staff have received all of the health-related training required by the State of New Jersey.

When the agency first began providing services it used Dr. Murphy, a local family practitioner for everyone who lived in their homes. Over the years this has changed. The people served by CSH have a wide variety of disabilities and many different health concerns. It has been increasingly difficult for the agency to find doctors, within a reasonable driving distance, who will accept Medicaid. Ninety percent of the people who live in CSH homes have Medicaid; ten percent have additional insurance coverage through their family.

The majority of the staff who work for CSH have been with the agency for less than two years. Most of those who have been with the agency for longer are currently in management positions. There are a few direct support staff who have been with the agency almost since it began. Most of the staff are very aware of the difficulties in making arrangements for health care.

Recently the State of New Jersey has begun to use managed health care plans, as the way that people who receive Medicaid will get health care. Many meetings have been held to explain the process to individuals and their families and to guardians. Everyone involved has selected an HMO. Each person now has a PCP.

Case Study Questions

1. Which people or families may have enrollment questions or concerns?

What questions or concerns might they have?

2. Which people might be able to get some help by calling their Health Benefits Coordinator agency?

Give an example of one situation. How might this person use the Health Benefits Coordinator agency?

3. Is there anyone who might need an exemption? Why might this person need an exemption?

4. Which people may want to choose a specialist as their Primary Care Provider? Why?

5. Why might Mike Choi or his support staff call a Care Manager?

What questions would you ask a Care Manager regarding Mike?

6. Which person might need specialty services?

What will this person/family need to think about when they choose a health plan?

7. Which people might need to check out a plan's arrangements for DME?

What questions would you ask a plan about DME for these individuals?

3.0 CHOOSING A HEALTH PLAN AND PRIMARY CARE PROVIDER

3.1 The Process

In New Jersey and most states, there is a Health Benefits Coordinator agency for individuals who receive Medicaid. The Health Benefits Coordinator agency will handle enrollment. The current Health Benefits Coordinator agency in New Jersey is called Maximus.

People will need to choose a:

1) Health plan
2) Primary Care Provider (PCP)

Choosing a health plan and Primary Care Provider is a very important process. People with disabilities will be given a choice of health plans and Primary Care Providers. It is very important to choose.

In New Jersey and most states, if someone does not choose a plan or PCP, one will be chosen for him or her. This is called automatic assignment. You do not want this to happen – the health plan and PCP may not be chosen based on the needs of the person – and might not be the best one for them.

Prior to enrollment, Medicaid will send the eligible person a letter indicating that they need to enroll in a health plan and choose a Primary Care Provider. The letter will also contain the timeline for enrollment and when the person needs to inform the Health Benefits Coordinator Agency of their choice. Individuals will also be given enrollment forms and a brochure from the Health Benefits Coordinator Agency with the names of participating health plans.

3.2 Decision Making for Agencies

Enrolling in managed health care is a major health care decision and a legal decision. **Who gets to make decisions**, including choosing plans, primary care providers, and other health care providers, is very important for people with developmental disabilities. These decisions need to be **individual** decisions and based on the needs of the person.

As a support provider, it is likely that you will be involved in the process of choosing health plans and PCPs. You can assist in the process and make recommendations. You can share information that will be useful in the decision making process. But you do not have the right to make the decision for the person. Usually, either the person or their legal guardian needs to make the decision. The person who can legally make this decision is called the Authorized Person.

> ✎Check with your agency about who can make the decision, whether it's the person with developmental disabilities, their family, and/or their legal guardian.

Once the decision is made to join a particular health plan and Primary Care Provider, people need to know that whatever plan and doctor they choose is where they will have to continue to go for their health care.

> ⇨**Example:**
> Rosa Hernandez used to go to a health clinic but choose Dr. Brown to be her new PCP when she enrolled in managed health care. Now she has to go to Dr. Brown – or the other doctors in his office - for all of her health care. She can't go to the clinic she used to go to, since she made another choice.

3.3 Decision Making for Individuals and Families

One decision that will have to be made is whether the person likes his/her current doctor and wants to stay with that provider. For people with disabilities, the choice of a plan may mean changing their Primary Care Provider or specialists. Sometimes a person will need to decide between keeping their Primary Care Provider or keeping a specialist. Sometimes a family will have to choose between keeping their child's doctor or their own doctor. If the person likes his/her current doctor, she/he can find out which plans their doctor participates in and which plans they recommend.

⇨Examples of things important in choosing a plan/doctor :

- What doctors are in the health plan
- PCPs and specialists
- What DME company they use
- Location of doctor's office
- Geographic location
- if the person with disabilities lives in more than one location – the person lives in a group home but goes home for weekends with family in another part of the state
- Accessibility of doctor's office

Other things to think about

The person with disabilities will need to select a new Primary Care Provider if…

- The individual's current Primary Care Provider is not included in the network of the health plan which otherwise best suits the person's needs
- The person does not have a good relationship with his/her Primary Care Provider, even if they have been using this physician for a long time and the physician is part of the chosen plan's network
- The person does not have a Primary Care Provider

The person can ask the current PCP to join a particular health plan. Some doctors may agree to join the health plan.

Selecting a new primary care provider:

1. Look at the provider directory for the health plan. You might also get help from the Health Benefits Coordinator, or a family member.
2. Call the office of the new physician to determine the attitude of the doctor and office staff about serving people with disabilities.
3. Ask about the physician's background, training, and credentials. Is the practice experienced in treating people with disabilities?
4. Confirm that the specific provider still has room in the practice to accept new patients under the health plan chosen. If you are a current patient, the provider may be allowed to accept you even if his/her practice is full.
5. Make an appointment as soon as possible.

The **most** important thing in choosing a health plan is the health needs of the individual.

Questionnaire:

What do you or your family member need from the health care plan? What is most important?

1) Do you or your family member have a regular primary care doctor?
❒ Yes
❒ No

If yes, is it important to you/their health that you/they stay with that primary care doctor, or should you/they try a new doctor?
❒ Important to my/their health that they keep the same doctor
❒ A new doctor might be able to meet my/their needs
❒ Don't know

2) Do you or your family member have a specific health condition or disability that may be served by a special department or "clinic" within a health care plan? (For example, Spina Bifida, Cerebral Palsy, Down syndrome, etc.
❒ Yes
❒ No
If yes, what _____

3) Do you or your family member see a specialist, or more than one specialist, often?
❒ Yes
❒ No

If yes, what type(s)
❒ Cardiologist
❒ Orthopedist
❒ Neurologist
❒ Allergist
❒ Other _____

If you or your family member have specialists, is it important to your/their health that you/they stay with the specialists, or could you/they see new specialists of the same type?

- ❒ Important to my/their health that I/they keep the same specialists
- ❒ New specialists might be able to meet my/their needs

4. Do you or your family member use a walker, a wheelchair, or a scooter to get around?
   - ❒ Yes
   - ❒ No

5. How do you or your family member get from place to place?
   - ❒ Drive
   - ❒ Someone drives me/them
   - ❒ Use public transportation
   - ❒ Use special transportation

6. Are you or your family member deaf or hard of hearing?
   - ❒ Yes
   - ❒ No

   Do you/they use a TDD or other means of assisted communication?
   - ❒ Yes
   - ❒ No

   Do you/they use a sign language interpreter?
   - ❒ Yes
   - ❒ No

7. Can you or your family member read and understand most printed information?
   - ❒ Yes what languages? _____
   - ❒ No

   If not, what type of information is best for you/them?
   - ❒ Braille
   - ❒ Audio Tapes
   - ❒ Computer Disks
   - ❒ Large Type
   - ❒ Other

8. Do you or your family member often need dental work?
   - ❒ Yes
   - ❒ No

   Do you or your family member need sedation for your/their dental work?
   - ❒ Yes
   - ❒ No

   What kind of sedation does your/their disability require? _____

9. Do you or your family member use any of the following equipment or supplies?
   - ❒ Wheelchairs, manual or electric
   - ❒ Respirators
   - ❒ Prosthetic devices (like an artificial leg or arm)
   - ❒ Ventilators
   - ❒ Diabetic supplies
   - ❒ Oxygen and related equipment
   - ❒ Diapers
   - ❒ Dietary supplements (like Ensure)
   - ❒ Other _____
   - ❒ Where do you/they get their equipment or supplies?

   _____

   Is it important to your/their health that you/they stay with that supplier, or would a new supplier be able to meet your/their needs?

   - ❒ Important to my/their health that they keep the same supplier
   - ❒ A new supplier might be able to meet their needs

10. Do you or your family member regularly take prescription medicine?
    - ❒ Yes
    - ❒ No

    What drug store or pharmacy do you/they use? _____

    Is it important to your/their health that you/they stay with that pharmacy, or would a new pharmacy be able to meet your/their needs?

    - ❒ Important to my/their health to keep the same pharmacy
    - ❒ A new pharmacy would be able to meet my/their needs

11. Do you or your family member regularly use nursing services or home health services?
❒ Yes
❒ No

Who provides these services? _____

Is it important to your/their health that you/they stay with that service, or would a new service provider be able to meet your/their needs?

❒ Important to my their health that I/they keep the same service
❒ A new service provider would be able to meet my/their needs

12. Do you or your family member regularly go to a physical, occupational, or speech therapist?
❒ Yes
❒ No

Who provides these services? _____

Is it important to your/their health that you/they stay with that service, or would a new service be able to meet your/their needs?

❒ Important to my/their health to keep the same therapist
❒ A new therapist would be able to meet my/their needs

13. Do you/they need to have medicine to relax them or make them sleep for most doctors' visits or procedures? (sedation)
❒ Yes
For what type of procedures?_____
❒ No

14. Do you or your family member regularly receive mental health or substance abuse treatment, such as counseling, or do you/they need to start?
❒ Yes
❒ No

Who provides these services? _____

Is it important to my/their health that I/they stay with that provider, or would another provider be able to meet you/their needs?

❒ Important to my/their health to keep the same provider
❒ A new provider would be able to meet my/their needs

15. Of items 1 through 3 and 8 through 14, which four are the most important to the person's health?
    1.
    2.
    3.
    4.

(Adapted from *To Your Health: Choosing the Health Care That Is Right For You*, Oregon Advocacy Center, 1994)

Worksheet:

Choosing a Health Care Plan

Work Sheet Directions:

1. List all health care providers an individual is currently using. Include the primary care physician, specialists, dentists, opticians, hospitals, clinics, rehabilitative and support services, as well as durable medical equipment providers.

2. Review the list and determine which services are most important and which the person would not want to, or should not change. Mark these essential services on the worksheet. Consider the possibility whether another doctor, such as the primary care physician or another specialty provider might provide any of these essential services, such as an annual eye exam.

3. Work with the Health Benefits Coordinator. Request provider directories for each health plan being considered by the individual. Directories are available through member services or the Health Benefits Coordinator. You can also call each physician/provider to ask which plans they participate in.

4. At the top of the form, in the columns, enter the names of the health plans.

5. For each health plan, go down the list of health care providers the individual is currently using and check the box if the physician, hospital, or service is included in the network of providers for that health plan.

6. Review the worksheet. Determine which plan includes most of the providers or services indicated as “must haves”. That plan may be best suited to the needs of the person.

7. The enrollment coordinator must be notified by the individual, family, or guardian of the choice of HMO and PCP. It could be with a form, in person, or over the phone.

Choosing a Health Plan Worksheet - SAMPLE

	Names of HMOs					
Health Care Providers *List all doctors, specialists, hospitals, clinics, nurses, medical equipment providers, etc. the person is using now or have recently used.*	Example: Acme HMO					
Primary Care Physician:						
Dentist:						
Specialists (list all):						
Nursing Services:						
Psychiatrist:						
Other Mental Health Services:						
Hospital Preference:						
Pharmacy Preference: Open 24 hours?						
Medical Equipment Providers:						
Any other things to think about: Example: Location – For someone living in a group home, do they live anywhere else part of the time, like with their family?						

(Adapted from *Choosing a Medicaid Managed Care Company: Making an Informed Choice: A Guide for Individuals with Mental Retardation or Developmental Disabilities*, Philadelphia Coordinated Health Care, 1996)

Choosing a Health Plan Worksheet

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Pharmacy Preference: Open 24 hours?						
Medical Equipment Providers:						
Any other things to think about: Example: Location – For someone living in a group home, do they live anywhere else part of the time, like with their family?						

(Adapted from *Choosing a Medicaid Managed Care Company: Making an Informed Choice: A Guide for Individuals with Mental Retardation or Developmental Disabilities,* Philadelphia Coordinated Health Care, 1996)

4.0 PROBLEM SOLVING IN MANAGED HEALTH CARE

So far we've talked a lot about how managed care is supposed to work. Sometimes people have problems getting what they need from their health plan.

Concerns that should be complained about:

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

You may need to support people with disabilities to exercise their rights to make sure they get what they need.

If these things do happen, there are steps that you can take to make the situation better.

4.1 How to get help if there are concerns, problems, or complaints

If you are an agency staff member, it is important to first identify:

✎Who will handle the problem?
There are many things you can do. First, find out from your agency how to handle the problem and who will do it. It is helpful if your agency has a specific person who communicates with health plans about concerns and problems.

As we've just discussed, problems in managed health care could range from being unhappy with the doctor to not getting referrals and being denied medical care. Every health plan has to have a process to allow people to complain. This process should be described in the member handbook. When appropriate, help the person with disabilities consult and read the member handbook.

Problems should be handled informally first, by talking with the Primary Care Provider, the Care Manager, or the health plan by telephone.

If problems still cannot be fixed at that level, there are other steps that can be taken. This process is more complex. It involves making a complaint to the health plan, writing letters and sending documentation. This is called a complaint and grievance procedure.

NJ HMO Consumer Bill of Rights

Members of Health Maintenance Organizations or any health plan that manages the use of services through provider networks, have important consumer rights including:

- The right to have a doctor – not an administrator – make the decision to deny or limit coverage
- The right to appeal a decision to deny or limit coverage, first within the managed care plan, then through an independent organization for a $25 filing fee (reduced to $2 for hardship)
- The right to no "gag rules". Doctors are allowed to discuss all treatment options even if they are not covered services.
- The right to receive up to 120 days of continued coverage – if medically necessary – from a doctor who has been terminated by a managed care plan
- The right to know how your managed care plan pays its doctors so you know if financial incentives or disincentives are tied to medical decisions
- The right to obtain a current directory of doctors within the network
- The right to have a choice of specialists following a referral
- The right of consumers with chronic disabilities to be referred to specialists who are experienced in treating those disabilities
- The right to access a primary care provider or back-up 24 hours a day, 365 days a year for urgent care
- The right to call 911 in a potentially life-threatening situation without prior approval from your managed care plan
- The right to have a plan pay for a medical screening exam in the emergency room to determine whether an emergency medical condition exists
- The right to no retaliation against you or your doctor for filing appeals

- *Chapter 38, NJ HMO Regulations*
Also reprinted in NJ Health Care Plans: Compare Your Choices, 1998.

Medicaid Protections

People who receive Medicaid have the same rights as anyone else in health care, such as The NJ HMO Bill of Rights, but they also have federal and state protections.

The federal protection is The Medicaid Fair Hearing, which is the largest source of rights for people who have Medicaid. Individuals with Medicaid can file for a Medicaid Fair Hearing at any time. The largest state protection is the Medicaid contract, which explains exactly what each health plan must provide for its members who have Medicaid.

If problems are encountered, there are many advocacy and state agencies who can be of help at any time in the process. These are listed on the next page.

SOURCES OF HELP AT ANY TIME:

- Health Benefits Coordinator agency (Maximus)
  Hotline: 1-800-701-0710

- The state Medicaid office, if the person receives Medicaid.
  The person could file for a Medicaid Fair Hearing at any time in the process.
  Medicaid Managed Care Hotline: 1-800-356-1561

- Care Manager at the health plan

- Advocacy agencies or legal aid
  In New Jersey, the Community Health Law Project, Legal Services of New Jersey, and Protection & Advocacy, Inc. (see Resource Guide for additional information).

- The person's employer or parent's employer or human resources department, if his/her health insurance is employer-based

- The state's commissioner of insurance office

- Your state might also have a Consumer Assistance Program or Ombudsman Office to help people who have problems with managed care.

Remember: Each person has the right to change their Primary Care Provider or their health plan. In New Jersey, a person may change either his/her health plan or PCP at any time. This is an important decision, like first choosing a PCP and health plan.

4.2 Steps in problem solving

In New Jersey, this is the complaint and grievance procedure for Medicaid. It is slightly different for people who have other types of insurance.

Steps to take with the doctor

1. When appropriate, help the person to discuss the problem with the Primary Care Provider.

   ✎If the person needs someone to speak on his/her behalf, consult with your agency, and/or the family, or the guardian.

2. Give reasons why you disagree with the doctor and provide copies of documents, like medical history if necessary, to support your point of view.

Steps to take within the health plan

1. The Care Manager at the health plan should be called to discuss the problem. The Care Manager may be able to talk with either the doctor or the health plan and find out what can be done.

2. If necessary, the next step is for the appropriate person to call the member services 800 number with their concerns and to make an oral complaint to the health plan. The person should ask for the name and the phone number of the person they speak with, and when they will get back to them. They should call again if the plan doesn't get back to them.

3. If the response from the plan's member services department is not satisfactory, the appropriate person can file a written grievance with the plan. Be sure to check the member handbook for the plan's procedures for this and include copies of documentation of the problem.

   In New Jersey, for Medicaid there are two stages to this grievance process. The first is called an Informal Internal Review (Stage 1 Appeal) and the second is a Formal Internal Review (Stage 2 Appeal).

Steps to take outside the health plan

1. For people who have Medicaid, the state Medicaid agency can be called to file for a fair hearing. Remember that you don't need to go through the other steps first.

2. For all individuals in New Jersey, there is a Formal External Review process (Stage 3 Appeal) where an outside organization reviews the case. People who have Medicaid could do this process instead of - or in addition to the Medicaid Fair Hearing if they choose.

Problem Solving: Case Study Situations

Situation 1

You have just returned from two days off and you are reviewing the communication logs for this time period. You read a note from this morning saying that Michelle Adams had a difficult time getting up this morning. She also did not want to go to work. You know that Michelle started this new job about two weeks ago and has been very enthusiastic about going.

When Michelle returns to her apartment a short time later you notice that she appears tired and pale. When you ask her if she feels okay she shrugs her shoulders but doesn't say anything. In her bedroom a few minutes later when you ask again if she feels okay she shakes her head indicating no and starts to cry. Michelle points to her abdomen and says, "It hurts."

You follow up with the staff who were working on the previous two shifts and find out that with the exception of what was written in the log, they did not notice anything unusual. Because you have known Michelle for about eight months, you know that the way she is acting today is quite unusual.

You follow your agency's procedure regarding follow up on a complaint of illness. You decide to call Michelle's primary care physician to get an appointment. The receptionist/nurse in the office gives you an appointment date for the following week.

1. Refresh your memory if necessary by reading in the earlier case study about Michelle and her agency.

2. What is the problem in this situation?

3. What would you say when the nurse/receptionist gives you the date for Michelle's appointment?

4. If the situation is not resolved while you are on the phone, what would you do next?

5. Who would you talk to in your agency?

Situation 2

Nate Whitman has Dr. Jones as his PCP. You have accompanied Nate to three medical appointments. During the initial appointment Dr. Jones asked you most of the questions. You did a good job assisting Nate to answer them and you thought that Dr. Jones was beginning to understand that Nate knew about his health and could answer his questions. At the second appointment the situation was the same. Following the appointment you called Dr. Jones office and communicated your concern to the nurse, she said she would make sure that Dr. Jones knew that he should talk directly to Nate. At the third appointment there was a new medical concern raised and Dr. Jones told you that he did not have time to explain things to Nate.

1. What steps should you take to resolve this situation?

2. What would you say to Nate about this?

3. What are Nate's rights as a health plan member?

Sample Telephone Dialogue - Agencies

Staff:

My name is Valerie Gibson. I work at Community Service Homes with one of your plan members. His name is Nate Whitman and his member # is 143-02-3456. We have a concern about his Primary Care Physician.

Plan:

Who is Mr. Whitman's PCP and what is the concern?

Staff:

Dr. Regis Jones in Cherry Hill. Mr. Whitman needs assistance going to the doctor, so I go with him. We have been there 3 times. Each time the doctor does not talk to Nate. He asks me the questions and talks only to me. I have mentioned this to the nurse and to Dr. Jones himself. The last time he said that he did not have time to explain things to Nate.

Plan:

Does Mr. Whitman want to change doctors?

Staff:

Yes, as soon as possible.

Plan:

Do you have a list of the other doctors in your area?

Staff:

I'm not sure, can you send me the most current one?

Plan:

I will put one in today's mail. Please call back with the new physician's name as quickly as possible.

Sample Telephone Dialogue – Individuals and Families

Parent:

My name is Valerie Parks. My daughter lives in a Community Service Homes apartment and she is a member of your plan. Her name is Tamara Parks and her member # is 156-02-3456. I am concerned because her doctor is not referring her for mental health care.

Plan:

Who is Tamara's PCP?

Parent:

Dr. Rene Johnson in Edison. Tamara has been treated for depression before but not as a member of this health plan.

Plan:

Is the doctor she saw previously part of our plan's network?

Parent:

Yes, I think so. This problem has been going on for a few weeks and I'm concerned.

Plan:

I will check into this for you and call you back.

Parent:

May I have your name and can you tell me when to expect a call?

Plan:

My name is Anita Evers and I will call you back tomorrow, probably in the afternoon.

Telephone Log Sheet - SAMPLE

Date: _____

Name of person you are calling for:_____
Membership number: _____

Phone number you called: _____
Name of person you spoke with: _____

1) Tell the plan about the problem that the person with disabilities is having:
   _____
   _____
   _____

2) Ask the plan what it will do to address the problem:
   _____
   _____

3) Ask the plan how long it will take them to get back to you:
   _____
   _____

4) Ask who will get back to you:
   _____

   Suggestion: put a note in your calendar to remind you when you were supposed to get a response. If you don't hear from the health plan, call back.

(Adapted *from Your Health Plan Handbook: How to Get the Health Care Your Family Needs From a Managed Care Plan*, Community Service Society of New York, 1998)

Telephone Log Sheet

Date: _____

Name of person you are calling for:_____
Membership number: _____

Phone number you called: _____
Name of person you spoke with: _____

5) Tell the plan about the problem that the person with disabilities is having:

_____

_____

_____

6) Ask the plan what it will do to address the problem:

_____

_____

7) Ask the plan how long it will take them to get back to you:

_____

_____

8) Ask who will get back to you:

_____

Suggestion: put a note in your calendar to remind you when you were supposed to get a response. If you don't hear from the health plan, call back.

(Adapted from *Your Health Plan Handbook: How to Get the Health Care Your Family Needs From a Managed Care Plan*, Community Service Society of New York, 1998)

4.3 You can make a difference!

You have to advocate for the health of the people with disabilities. There are some responsibilities you have in being an advocate for yourself and others.

1. Follow your state and agency's rules for guardianship and decision making. Clarify your role with health providers so they know who can make health care decisions or give consent.

2. Help the person to be an informed consumer of health care. Help the person read the member handbook and learn the plan's rules. Help them to learn about their own health and to speak up for themselves whenever possible.

3. Learn the plan's rules yourself so you can help the person you support to be resourceful in using the health plan.

4. Know which doctors, hospitals, pharmacies, and other providers participate in the health plan.

5. Help the person to ask questions and tell the PCP about any concerns they may have; speak on their behalf when necessary.

6. Show up on time for appointments and call to cancel appointments that cannot be kept.

7. Record information in health care records, agency logs. Also record any contacts you have with the health plan.

8. Call member services or the care manager at the health plan when there are questions or problems.