

# THE MANAGED HEALTH CARE CURRICULUM:

*Supporting People  
with Disabilities  
to Utilize  
Managed Health Care*



## PART II

### LEARNING HOW TO IMPROVE HEALTH AND WELL BEING

### WORKBOOK

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## WORKBOOK

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## INTRODUCTION

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This curriculum is designed to enhance the skills necessary to support people with developmental disabilities in using managed health care, taking care of health problems, and becoming and staying healthy.

Participants in this training session will have an opportunity to learn how to:

- Help people get and stay healthier
- Communicate more effectively about health care needs
- Help people with disabilities get more out of managed health care

Today's training is divided into 3 sections:

- Health and Wellness
- Navigating the Managed Health Care System
- Interacting with Managed Health Care: Your Role

# 1.0 HEALTH & WELLNESS

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## 1.1 What is Health?

Let's first look at how health is defined by different people.

The World Health Organization defines health this way:

*“Health is a complete state of physical, mental and social well-being and not merely the absence of disease”*

Bob Williams, former Commissioner of the Administration on Developmental Disabilities and a man with severe physical disabilities sees it this way:

*“Disability is not the opposite of good health”*

It's important for all of us to be aware that many disabilities include medical or health problems, but a person can have a disability and also be healthy.

## **1.2 Learning Your Health Beliefs**

Each of us has a set of beliefs about health and illness that come from the culture in which we grew up, our family, our community, and our experiences. Being aware of those beliefs can make us more effective in supporting people with developmental disabilities in getting the health care they need. Understanding these values, beliefs and experiences also makes us more effective in achieving good health for our families and ourselves.

## **Families and Health Care: A Multicultural Exercise**

1. What did sickness mean in your family?
2. What did you do when you got sick as a child?
3. How were you treated when you were sick?
4. Who made the decisions about illness and health care in your family?
5. What home remedies did you use?
6. Did you go to the doctor as a child? If you went to the doctor, did you have a doctor that was your regular doctor? Did you go to a clinic?
7. Did your family use the emergency room? Did you family use hospitals?
8. Did anyone in your family have a disability or chronic illness?
9. Was there any one in your family with mental illness or with substance abuse?
10. How are the elderly treated in your family?
11. How does your family deal with death?

## 1.3 Paying Attention to Health

An important role for direct support staff is to help the people they work with get healthier and stay healthy. Direct support staff have an important role to play in recognizing health problems and assisting people in getting the care they need when they are ill.

To help people with disabilities to be healthy, you need to know the person so you understand what their typical or normal health is like.

For each individual you work with, there will be things about that individual's health that are unique and you must learn those things.

You must also be a good observer and a good communicator about health.

The provider agency you work for must have clear policies for dealing with health care situations and managed care.

 As a direct support worker you are responsible for knowing your agency's policies about health care and decision-making.

## Some Indicators of Health or Health Problems

### Physical Health

- **Changes in body temperature and fever**
  - Know where the thermometer is and how to take temperature
- **Changes in appetite**
- **Changes in mood or behavior**
  - Is the person more active or less active?
  - Are they quieter than usual?
  - Are they communicating less or less effectively?
  - Do they seem tired or listless?
  - Are they less able to cope with their daily routine?
- **Appearance or increases in self injury**
  - The appearance of self-injurious behavior, an increase in existing behavior or unusual negative behavior may indicate the presence of an underlying health problem
- **Changes in sleep patterns**
  - Difficulties in falling asleep or staying asleep
  - Restlessness /wakefulness
  - Differences in duration or quality of sleep
  - Continuously waking up tired-sleep not being refreshing
- **Changes in appearance**
  - Color of skin
  - Rashes
  - Eyes - bloodshot or runny
- **Changes in bowel or bladder habits**
  - Is the person constipated or have diarrhea?
  - Does the person have to urinate more frequently?
  - Is a person having toilet accidents, when they previously didn't?

- **Changes in breathing**
  - Difficulty in breathing?
  - Shortness of breath?
  - Shallow or rapid breathing?
  
- **Complaints of pain**
  - Headache
  - Earache
  - Toothache
  - Sore throat
  - Stomach ache
  
- **Changes in motor ability**
  - Difficulties in moving around
  - Difficulties in balance
  
- **Other symptoms of illness**
  - Nose – running or congested
  - Cough
  
- **Seizures or other conditions**
  - Increase or other changes in seizure patterns
  
- **Changes which might be caused by medications**

## Mental Health

People with developmental disabilities may have mental health problems just like people without developmental disabilities.

People with developmental disabilities may have difficulty communicating their mental health needs.

Other characteristics of developmental disabilities, such as limitations in communication or cognitive impairments may make it harder to identify mental health problems.

The following are only **EXAMPLES** of symptoms that may indicate a mental health problem; having any of these ***does not mean*** that the individual has a mental health problem. Mental health problems ***are not limited*** to these examples.

Mental Health Symptoms ***may*** include:

- Changes in sleep patterns or habits
- Increased or decreased sleeping
- Changes in behavior
- Changes in mood
- Changes in activity level
- Lethargy
- Extreme agitation
- Hyperactivity
- Changes in appetite
- Increases or decreases
- Changes in eating
- Changes in interest in regular activities

## Dental Health

The dental needs of people with developmental disabilities include:

- Adequate and thorough self-care and oral hygiene
- Regular check-ups and professional cleaning
- Care for dental problems

People with developmental disabilities have the same dental needs as other people but also may have additional dental needs because of their disability.

⇒ **EXAMPLES of specialized dental needs may include:**

- Gingivitis - inflammation of the gums that is a side effect of some seizure medications.
- Increased dental caries (cavities) in conditions that cause excessive drooling.
- Adapted dental techniques to accommodate people with spasticity.
- Adapted dental techniques, including behavior modification to accommodate people who have difficulty tolerating dental procedures or people with behavior difficulties.
- For some individuals, sedation maybe required for dental procedures.
- Physically accessible dental chairs.
- People with developmental disabilities may also have difficulty communicating dental pain or discomfort.

⇒ **EXAMPLES of dental symptoms can include, but are not limited to:**

- Difficulty in chewing
- Refusing to eat certain **types** of food: i.e., hard foods or very cold foods
- Not eating
- Redness, irritation, or bleeding of gums
- Foul breath odor
- Swelling
- Hands in mouth
- Complaining of tooth pain by verbalizing or pointing
- Fever
- Increased drooling
- Holding head
- Self-injurious behavior, including hitting or banging head



## **Situation 2**

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.

1. Make a list of the indicators of health problems for Michelle.
  
  
  
  
  
  
  
  
  
  
2. List the first 3 things Michelle's staff should do.

## 1.4 Communicating with Health Care Providers

Communication is the exchange of information. Communication can be spoken, written or expressed through behavior.

### Communicating Your Observations and Making Appropriate Responses

 You and your agency must know and follow the health plan's (the HMO to which the individual belongs) policies and procedures for accessing care for routine, urgent and emergency situations. You must know the health plan's policy for when to call the doctor or go to the emergency room.

 You must also know the policies and procedures of the community provider agency you work for about contacting health care providers and your supervisors, and documenting changes in health status and health care information.

## Calling the Primary Care Provider (PCP)

When you see health changes that need to be communicated or checked with the person's health care provider (PCP):

1.  You need to follow agency and health plan policies and procedures.
2. If you are not the person to make the call give the information to the person designated to make the call.
3. If shifts change, or you will not be available, and you are awaiting a return call, alert the next shift to the call. It is your responsibility to give the appropriate information to whoever will get the call.

## When You Call the Primary Care Provider (PCP)

1. If it is during the health plan's regular hours you may reach the PCP directly or you may reach someone who takes call for triage. Triage is the process of deciding the degree of urgency of a call or situation.
2.  Each health plan handles its call procedures differently. You need to learn the plan's procedures.
3. If it is after hours when you call you will reach the health plan's on-call system or person. One of the benefits of managed health care is that health plans are required to provide 24-hour a day coverage.
4. On-call services are not designed to deal with routine calls, such as prescription refills. For routine calls it is best to call during the plan's regular business hours. This help assures that there will be continuity for the person.

## Making Your Call Effective

1. Introduce yourself when you call:  
*“This is Maria Rodriguez”,*
2. Your role:  
*“I am a direct care worker at the Bailey Street group home”*
3. Who you are calling (the person’s PCP):  
*“I’m calling Dr. Zamora”*
4. Who you are calling about:  
*“about his patient Theresa Greene”,*
5. Any relevant information about the person’s disability:  
*“a woman with Down’s syndrome”*

This is important because some health conditions may be more serious or of more concern for people with certain types of disabilities.

This is called co-morbidity, where having two conditions at the same time makes each of them more complicated or more serious.

Some people with developmental disabilities might have special health conditions directly related to their disability.

**Do not stereotype** by disability or make diagnostic assumptions.

## The Goal of Your Call

Your goal is to describe the changes you see to the PCP's office.

You should be able to tell them:

1. Temperature
2. Symptoms such as pain, rashes, increased seizures, etc.
3. How long they've had the symptoms (duration)
4. How severe their symptoms are (intensity)
5. Whether the symptoms are getting better or worse (progression)
6. Medications they're taking
7. Is anyone else sick in their immediate environment: other resident, staff or friend?

## 1.5 Health Promotion and Wellness

### Managed Care and Health Promotion

Traditional fee-for-service health care mostly focuses on treating illness.

An important aspect of managed health care is its emphasis on improving health, staying healthy and preventing illness.

Health researchers estimate that lifestyle choices influence 40-60% of people's health outcomes. Maintaining an appropriate body weight, a healthy diet, regular exercise and not smoking are examples of important lifestyle choices that affect health and well being. Exercise is important for weight control, prevention of some of the effects of aging, including osteoporosis and also for psychological well being.

A person's health plan might have programs aimed at health promotion. Some examples are:

- Smoking cessation programs
- Nutrition/diet programs
- Exercise programs

Sometimes the health plan runs these programs; sometimes the health plan might pay for the person to use a program in the community, such as a health club or Weight Watchers.

A person with disabilities could use these programs to help stop smoking, lose weight, or become more physically fit.

As a direct support worker you may have a role in helping the person with disabilities utilize these programs. Some roles direct support workers may be called on to play include:

- Encouragement and reminders
- Helping someone get comfortable in a community setting, such as a YMCA/YWCA; serving as a kind of “coach”
- Participating in a program with the person, such as walking together 20 minutes a day
- Teaching about better nutritional choices or teaching how to cook healthy foods
- Modeling good health habits

## Healthy Habits

The goal of health promotion is living a healthy lifestyle. Developing good health habits contributes to staying well and maximizing an individual's functioning.

The following are things or habits all people should do to stay healthy. People with disabilities should be encouraged to be as healthy as they can be. People with disabilities may never have been taught these things. They may need to learn them, or be supported in remembering or utilizing them.

Your expertise as a direct support worker can help the people with disabilities you work with incorporate these habits in their daily lives.

Here are some examples of healthy habits. They are written in the style you would use in working directly with a person with a developmental disabilities.

## Healthy Habits

1. Using proper hygiene prevents you from getting sick or getting an infection. It can also make you feel good about yourself.
  - Wash hands after going to the toilet.
  - Wash hands before you eat.
  - Wash hands before you prepare and cook food.
  - Take a bath or shower and wash your hair every day.
  - Change underwear and clothes.
2. Don't smoke!
3. Get regular exercise.
4. Eat a healthy diet.
5. Use seat belts every time you ride in a car or a van.
6. Don't drink alcohol and drive a car.
7. Don't drink alcohol and take medication at the same time.
8. Don't use drugs.
9. Practice "safe sex" so you don't get sexually transmitted diseases or get pregnant.
10. Make your home safe so you won't have accidents.
  - Get a smoke alarm, hang it up in your house. Check the batteries every month.
  - Make sure your house or apartment has a fire extinguisher.
11. Take care of your teeth.
12. Use sunscreen when you are out in the sun.

13. If you are a woman, do regular breast self exams. If you are a man, do regular testicular exams. Your doctor or nurse can teach you how.
  
14. Get regular checkups at the doctor and follow the doctor’s advice for screening tests.
  
15. Make friends who can be a “support system” for you.

(Adapted from *Let’s Talk About Health: What Every Woman Should Know*, Arc of New Jersey, 1996)

## Preventing Secondary Conditions

*“Secondary disabilities are those conditions that are related to an individual’s primary disability and can result in further deterioration in health status, functional capacity, and quality of life”*

*-Institute of Medicine, 1991*

The terms “secondary disabilities” and “secondary conditions” are used interchangeably; they mean the same thing.

For secondary conditions that are not preventable, their impact can be minimized with appropriate intervention and/or treatment.

Secondary conditions, if not prevented or treated when they occur, can cause a decline in a person’s abilities or health.

Secondary conditions can also have a great impact on the individual’s quality of life.

### ⇒ **Examples of secondary conditions include:**

- Pressure sores from improper positioning in wheelchair
- Chronic constipation from lack of fiber in diet or lack of exercise or limitations in mobility
- Contractures from improper positioning
- Recurrent bladder infections in people with neurogenic bladders, (often affecting people with spina bifida)
- Neck pain or osteoarthritis from poor body mechanics when using assistive technology devices

Secondary conditions are often thought about primarily in terms of physical disabilities, but people with cognitive impairments may also acquire secondary disabilities.

⇒ **Examples of these include but are not limited to:**

- Depression
- In people with Down Syndrome: hypothyroidism, instability of the neck, early aging, chronic myelogenous leukemia
- In people with Fragile X Syndrome: psychiatric disorders

It is important to be aware of secondary conditions and do everything possible to prevent them. Everything else we've talked about – paying attention to changes and staying healthy - will prevent secondary conditions.

## **2.0 NAVIGATING THE MANAGED HEALTH CARE SYSTEM**

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### **2.1 Access to Health Care**

Helping people with developmental disabilities get connected to the health care they need often involves the need for good communication skills. Clear communication is important and increases access to health care whether by the person with disabilities, the person helping the individual, a family member, direct support staff, case manager, or social worker.

Getting connected to health care may be finding the right health care provider, making appointments or going to appointments and having the necessary information.

Once a person gets "connected" and has access to health care, good communication is also important to get the best results from health care. This is true for anybody, especially the person with a developmental disability. Direct support workers and families can also use their communication skills to facilitate the active participation of the person with a disability in their own health care, even if the person has cognitive or communication limitations.

Managed health care especially relies on good communication from the patient and the person accompanying them, if necessary. Good communication is helpful for any type of health care or other service.

Communication is also an important tool in ensuring that the rights of people with disabilities are protected in managed health care. Good communication is a responsibility of both health care providers and patients and those who support them in using health care.

## 2.2 Health Care Providers

Health Care Providers are the professionals who deliver medical and health care. They may be physicians, doctors, nurses or other types of health providers.

### ⇒ Examples:

- Doctors: M.D. (Medical Doctor)  
or D.O. (Doctor of Osteopathy)
- Nurses: R.N (Registered Nurses)  
or C.N.P. (Clinical Nurse Practitioners)

### Health care providers differ in the age of the patients they treat.

- Pediatrician  
provides health care to infants, children and adolescents
- Internist  
provides health care to adults
- Family Practitioner/Family Physician  
provides health care to people of any age and often takes care of all the members of a family
- Geriatrician  
specialist in the care of elderly people

### Health care providers differ in the types of conditions they provide care for.

#### ⇒ Examples of specialists are:

- Cardiologist...specializes in the heart
- Dermatologist...specializes in skin conditions
- Neurologist...specializes in the nervous system, including seizure disorders

## Examples of Health Care Providers by Area of Specialty

PRIMARY CARE	ADULT	PEDIATRIC
Physician	Family Practice Physician Internist Generalist	Pediatrician
Nurse Practitioner	Family Nurse Practitioner (FNP) Geriatric Nurse Practitioner (GNP) Adult Nurse Practitioner (ANP)	Pediatric Nurse Practitioner (PNP)

SPECIALIZES IN CONDITIONS OF:	PHYSICIAN	OTHER
Eyes/Vision	Ophthalmologist	Optometrist
Ears/Hearing	ENT (Otolaryngologist)	Audiologist
Nose & Throat	ENT (Otolaryngologist)	
Nervous System/Brain	Neurologist	
Emotion/Behavior	Psychiatrist Behavioral Neurologist	Psychopharmacologist Psychologist Psychiatric Nurse Social Worker
Heart	Cardiologist	
Stomach/Colon/Intestines	Gastroenterologist	
Skin	Dermatologist Plastic Surgeon	
Lungs/Chest	Pulmonologist	
Bones/Tendons (also rehabilitation and equipment)	Orthopedist/Orthopedic Surgeon	
Kidney	Nephrologist	
Urinary Tract	Urologist	
Blood	Hematologist	
Hormones	Endocrinologist	
Women's Health	Gynecologist, Obstetrician	Nurse/Midwife

Children's Health	Pediatrician, Pediatric Specialist	
Foot Care	Podiatrist	
X-Ray	Radiologist	
Elder Care	Geriatrician	Gerontologist
Head/Neck/Back (also rehabilitation and equipment)	Physiatrist	Chiropractor Physical Therapist
Diet/Nutrition		Dietitian, Nutritionist
In-patient hospital care	Hospitalist	

(Adapted from *Communicating for Health: A Residential Resource Manual*, Shriver Center UAP, 1990).

## 2.3 Primary Care

### The Primary Care Provider

In managed care, it is important to understand the difference between Primary Care Providers and specialists.

The Primary Care Provider is the person's regular doctor or nurse. The Primary Care Provider provides care for their basic health needs and also coordinates all other health care services. To go to a specialist for other types of health care services, there must be a referral from the Primary Care Provider.

In some states, including New Jersey, a specialist may serve as their Primary Care Provider, if the person with disabilities chooses this option and the specialist is willing to provide all of the primary care required.

The Primary Care Provider will coordinate all medical care, including routine physicals, preventive health services, referrals to specialists, and hospital visits, even emergency room visits.

In managed health care, Primary Care Providers are often referred to as “PCPs”.

## Primary Care Appointments

The Primary Care Provider should be called when the person with disabilities:

- Is sick or hurt
- Needs a check-up
- Needs immunizations
- Needs prescription drugs or refill
- Needs a referral to see another doctor
- Needs advice about health problems

(Adapted from *Your Health Plan Handbook*, Community Service Society of New York, 1998)

Primary care visits are appointments with the individual's regular health care provider, the PCP. There are different types of primary care appointments. Sometimes the primary care appointments are with the PCP, sometimes with others in their office.

- Primary care appointments can be scheduled on a regular basis:

⇒**Example:**

Dr. Jones, "we'll check John's blood pressure every 3 months to make sure his blood pressure medicine is working. If he has any trouble in between checks, make an appointment and have him come back sooner".

⇒**Example:**

Sue goes to her PCP's office every week for the nurse to give her allergy shots.

- Primary care appointments are also scheduled when someone gets sick or there is a change in the person that could be the sign of illness. This is called urgent care.
- Primary care appointments are also scheduled for yearly physical exams or to complete medical forms for a new program, such as school or work.

## **Making the First Appointment**

Especially for a person with developmental disabilities, it is important to schedule a first appointment – an initial visit with the Primary Care Provider (PCP) they have chosen or been assigned.

It is important to schedule this initial visit as soon as the person becomes a member of the managed care plan. Don't wait until the person is sick or when their annual physical is due. Schedule the initial appointment with the Primary Care Provider early on so that the health care provider gets to know the person and learns about their health care needs before they are ill. It is also an opportunity for the person with developmental disabilities to get to know the PCP and the PCP to get to know the person, something that may take some time.

The first appointment with the Primary Care Provider establishes a baseline – what the person with disabilities is like when they are not ill. This helps the PCP, so that when the person is sick, they can have a better understanding of their typical health and behavior. This is important for all people, but especially people with behavior or communication challenges.

### **Phone call dialogue to make first appointment**

A staff member in a community residence is calling a health care provider. Rob Jenkins, who lives in the home, has recently become a new member of a managed care plan. Dr. Hill is the Primary Care Provider (PCP) who Rob has selected.

Health Care Office Receptionist: Hello, Prime Medical, May I help you?

Residential Staff Member: Hello, this is Rachel Manning, I'm calling to set up an initial appointment for a new patient of Dr. Hill's. His name is Rob Jenkins. Rob lives in a Care Services community home and I am a staff person who works with Rob.

Receptionist: I need to get some information about Mr. Jenkins. Which Health Plan does he belong to and what is his current problem?

Residential Staff Member: He's with Advantage Health. He is not sick; we want to make an appointment for an initial visit so he can get to know Dr. Hill.

## 2.4 Specialty Care

### Accessing Specialists

Managed health care provides specialty care through specialists in the plan's network.

In managed care, the person with developmental disabilities, as all other patients in managed care, needs the permission of their PCP to be seen by a specialist.

Managed health care controls access to specialists through the Primary Care Provider. In managed health care, the Primary Care Provider has to give permission – with a Referral - for the individual in the HMO to see a specialist.

The process of needing referrals is to limit unnecessary specialist visits and coordinate care so the PCP knows what is happening with the individual. Controlling access to specialists is also a way that managed care tries to hold down health care costs.

A way that managed care is different from fee-for-service health care is that under managed care the Primary Care Provider (PCP) will provide care for certain conditions previously treated/ managed by specialists.

⇒ **Example:**

Brian Williams' seizures are under good control with medication. His PCP manages the condition on an ongoing basis. Once a year, Brian sees his neurologist for evaluation and follow up.

### ★ **Health Hint! Visiting Specialists**

If the person with disabilities sees the specialist one time or for a once a year visit, they may not know the person very well or at all. In this situation you need to be even more prepared for visits. In addition to bringing the referral form, bring the person's medical history, recent lab results and a list of current medications. Sometimes the lab results done by the PCP will be adequate, other times they will need to draw new blood or urine samples, etc. You should alert the specialist if the individual is has difficulty during health care visits or there are other things he/she should know ahead of time.

## Referrals

A Referral Form must be presented at the office of the specialist, laboratory or x-ray department. Most offices will cancel the appointment if you don't bring the form with you or it has not been sent electronically by computer or fax.

Referral forms are specific to each HMO. The information on the referral form usually includes identifying information for the patient, the name of the Primary Care Provider, the reason for referral, the number of specialist visits the form covers, for example, “the number of visits authorized” and sometimes some brief background medical information. Most referral forms have space for the specialist to write their findings and comments. Usually referral forms come in multiple copies so that there is communication back to the PCP.

For people with developmental disabilities it's a good idea to request a copy of the completed referral form so that the information is up to date. Helping someone follow the referral process and keep track of the appropriate forms and procedures is an important part of gaining access to health care.

## ★ **Health Hint! Referral Forms**

People with developmental disabilities who go to the doctor by themselves may need to be reminded to bring their referral form with them to a specialty appointment.

### **Suggestions**

Make sure the person keeps the referral form in a safe place, where they can find it and remember it. If they have a wall calendar, try clipping the referral to the calendar. Where the appointment is written on the calendar, also write in "bring the referral form". For people who have difficulty keeping track of paperwork, you can ask the primary care doctor or her office to send the referral form directly to the specialist.

### **Community residence**

It's important to keep track of the referral form. Find a way to keep track of the form and make sure it goes with the individual to the appointment. Try keeping it in their notebook or chart. In the calendar or daily or weekly planning log make a note next to their appointment to bring the referral form and where it is being kept.

### **Families**

Keep a notebook or folder of health information. The referral form can be kept in there. For everyone - it's a good idea to write a reminder on the calendar to bring the form.

## 2.5 Using the Emergency Room

One of the changes in managed health care for people with disabilities is that people will not have to resort to using emergency rooms for routine health care.

Emergency rooms are not good for routine health care because:

- They do not provide continuity of care
- They do not provide follow-up care for the condition treated
- They are busy and crowded, making it difficult to establish rapport and communication between health care provider and patient
- They are an expensive and inefficient way to deliver routine care

Emergency rooms are for urgent and emergency care. Some plans require pre-authorization – permission ahead of time - for emergency room use.

-  Learn and follow the health plan's procedures for using emergency room care.
-  Find out and follow the procedures and regulations of the community provider agency for whom you work.

New Jersey follows the Prudent Layperson Standard for emergencies in the Medicaid contract. 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 manifest 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.

These are examples only.



You must follow procedures by both the health plan and your agency independent of this training.

An advantage of managed health care is 24 hour coverage, creating options for care that do not depend on the emergency room.

## 3.0 INTERACTING WITH MANAGED HEALTH CARE: YOUR ROLE

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### 3.1 Making Appointments

#### ★ **Health Hint! Get the Most out of Appointments**

Cluster health services needed by the individual with developmental disabilities, so primary care appointments are efficient and the individual doesn't have to go to the doctor more often than is necessary. Make a list before the going to the appointment.

#### ⇒ **Example:**

Steven Randolph needs to go for his annual physical. His support staff should help him to make sure that at the same visit:

- His rash is checked
- His prescriptions are renewed

The individuals you serve will appreciate not having to go to the doctor so often and the PCP and their office will appreciate it too. Also, if a person needs sedation, arrange to have more than one procedure done at the same appointment, if possible.

## **3.2 Accompanying: Bringing Someone to a Health Appointment Is More Than Just Transportation**

In community residences, taking someone to a medical appointment, shouldn't just be seen as transportation - unless the individual with a developmental disability is very independent and truly only needs transportation. Taking someone to a medical appointment is an important job - not just the assignment for the most inexperienced or newest hired. The staff member who takes someone to health appointments should be someone the person is comfortable with and who knows their history and conditions.

There are things you need to bring and information you need to have before and during appointments. You also need to bring information and instructions back to your agency from the health visit.

## 3.3 Health History

People with developmental disabilities, especially those who have been institutionalized may not have a complete health history or may not know their own health history. Health care providers need the person's history to make good decisions about their health care.

### **For the initial primary care appointment:**

Bring a complete health history or send it before you go. Include any new information about health problems or changes in behavior, habits, mood, sleep appetite, or weight.

### **Tips for Gathering Health History**

#### **Parents of young children:**

Start maintaining a notebook with all the child's health care information. Special Child Health/Maternal & Child Health case managers or Early Intervention personnel need to encourage parents to keep health information.

#### **People leaving institutions:**

Case managers and residential services providers should assure that they have a complete individual health history and family health history so that past information from their care, while institutionalized, doesn't get lost. Guardians and families may be a source of good information. Families and guardians should also be given a copy of this information and make copies available to new services.

#### **When Moving from Home to a Community Residence or Alternative Living Arrangement:**

When a person leaves their family home to live in an alternative living arrangement is an important juncture to make sure that their medical and health history is put down on paper, if that had not happened earlier.

## 3.4 Preparing for the Health Visit

### Gathering information

Here are some things to think about and do in preparing for a health visit.

1. Why is this person coming to the doctor at this point?
2. What is bothering them? How do you know? Can they tell you in words? Do they initiate the information or do you notice something and then question them about it?

*If they don't communicate in words, what clues help you?*

- Changes in their behavior
  - Level of activity
  - Skills decrease
  - Changes in sleep patterns
  - Changes in appetite
  - Changes in personality
- Duration: How long has this been going on?
  - Intensity: Is it the same, better or worse?
  - Time of Day: Is it worse or better at different times of the day
  - History: Is this something the person has had before?
- Specific emotional events
  - Loss of friends or family
  - Staff changes
  - Loss of job
  - Weight changes
  - Habit changes - bowel or bladder
  - Personality changes - aggression or passivity or withdrawal

3. Bring a list of current medications, when prescribed and by whom - or bring all prescription bottles
4. Consult with others who know the person: parents, guardians, employment staff

### **Prepare the person for the health care visit**

Prepare the person with developmental disabilities as much as possible for the health care visit. Tell them where they will be going, who they are going to see, and what might happen during the appointment.

## 3.5 Smoothing the Way

Getting there on time is an important part of getting health care. Call for directions if you don't know the way.

Other questions to ask:

- Ask for information on parking. If you drive a van, can the garage or parking deck accommodate its height?
- Is the appointment near rush hour so you need to allow additional time?
- For people with mobility problems, what is the closest entrance to the provider's office?

## 3.6 During the Health Care Appointment

### Arrangements

The following are some considerations about the arrangements for and during the health care visit.

- Does the person need to be accompanied into the actual visit?
- Does the person need to be accompanied for the whole visit - interview and physical exam, or can you stay only for the interview and come back for the recommendations?
- Privacy considerations - sending staff of the same or opposite gender.
- What makes the person comfortable?

### Model appropriate communication

Don't talk about someone as if they aren't there.

Don't assume, because people do not communicate verbally that they can't understand.

Ask direct questions of the person with developmental disabilities. Look at the person when you talk to them. "The doctor wants to know if your stomach hurts when you go the bathroom?"

If you are replying to a question, use the person's name. "I think John feels he is getting better".

Encourage the person to communicate with the provider. "Jane, do you think you could tell Dr. Smith what you told me this morning about your headache?"

Be respectful. Be patient.

## **3.7 Following Through and Following Up: Getting Information From the Health Care Provider**

### **1. Listen actively.**

Health Care appointments, especially under managed health care are time limited, so the information given at the end may be rushed.

### **2. Ask questions if you don't understand a word or other information.**

"Dr. you said Bill has gastric reflux. What is that?"

If something is very complicated and the health care provider is not going to be able to stay and explain things to you and the person with disabilities, ask if there is a nurse or someone else who could explain this more. If they are not available then, arrange a time when you or someone else could call for additional information. Special needs care coordinators can often help with this type of clarification.

### **3. Write things down.**

That will help you remember details and you can show your notes to someone else. You may also need the information to enter into the log of the group home or apartment. If the terms are very complicated, ask the health care provider to write them down.

### **4. Clarify the limits of your role and what you can and cannot do.**

Health providers may not be that familiar with working with direct support staff or advocates. Explain who needs to give consent for procedures. If you are not the authorized person, you cannot give consent for procedures. Despite pressure to get a procedure done, don't be bullied into signing a consent if you are not the authorized person. You have an important role in protecting the individual's rights.

 You need to know who is the authorized person for decision making.

## **5. Accountability for compliance.**

It is very important to follow through with all prescribed treatment and recommendations from health providers. There are many consequences if treatment is not followed. The person could get sicker, or the problem could get worse. Doctors will stop seeing a patient if they are not getting their medication or other treatment is not being followed.

## **6. Cancel appointments if it becomes necessary.**

Health plans and health provider's offices have rules for how much notice they need to cancel an appointment. You need to follow these rules and be courteous because your behavior helps shape the image of the person with disabilities.

## **Case Study**

### **Situation 1**

Tamara 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 her 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 doctor that her Father sees, he knows her and relates to her well. Dr. Woods, the cardiologist is not participating in the same plan as Janet's primary care physician, 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 its 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 or been assigned to an HMO. Each person now has a PCP.