

PROVIDING RESIDENTIAL SERVICES IN COMMUNITY SETTINGS:

A Training Guide

Developed and Endorsed by
Michigan Department of Community Health



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PREFACE

You have demonstrated a commitment to providing quality mental health services and supports in community settings.

This training guide includes eight modules designed to be used by people providing direct care in community residential settings.

People providing direct care have taken on an important role and accompanying responsibility to be prepared to support individuals with disabilities in their homes and community settings. This training guide is intended to help you to provide the best services and most effective support possible.

This guide was developed and endorsed by the Michigan Department of Community Health, as a training tool for the benefit of persons who work with consumers of mental health services in community-based programs. It uses examples of what the department considers to be best practices. It is not intended to be the policy, procedures or care and treatment guidelines that may be provided by your employer.

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**INTRODUCTION TO RESIDENTIAL
SERVICES IN COMMUNITY SETTINGS:
YOUR ROLE AS DIRECT CARE STAFF**

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THE PHILOSOPHY AND ROLE OF RESIDENTIAL SERVICES

INTRODUCTION

This section introduces you to your role as a direct care giver. Topics match the responsibilities you will have when providing services to persons who are mentally or developmentally challenged. After you complete this section, you should have a good idea of your day-to-day responsibilities as providers of direct care.

ASSESSMENT

Successful completion of this module is based on passing an objective test.

- ▶ **At the end of this section, you should be able to:**
 - **Define integration and understand the importance of integrated social, residential, school and work options;**
 - **Identify two primary goals of teaching daily living skills to persons living in community residential settings;**
 - **Recognize features of a positive living environment;**
 - **Recognize differences between institutional and community residential settings.**

Overview

Daily activities, events, talking to and living cooperatively with others is what we mean by **INTEGRATION**, or living in a community residential setting.

These activities can include making a cup of tea, talking with a friend, cleaning up your room, regular washing of soiled laundry, or eating meals together. These are activities we all do in everyday life. Life is coping with joys and frustrations, with the exciting and the boring, and most of all, with change. We share in the responsibilities and satisfaction of creating a positive living environment.

To integrate means to blend into common and equal membership in society.

Institutionalization

Institutions foster a life of passiveness and dependence. People do not have to be active in their own care, or do anything to get needs met.

Institutionalization occurs when people live in places other than their own home and come to depend on others to take care of them. They become unable to take care of themselves or understand how to get their needs met in positive ways.

When individuals are institutionalized, most daily living activities (meals, changing beds, washing clothes) are done for them. Individuals have few responsibilities. Group outings outside the institution are often highly supervised and rigid. There is little room for individual interests or needs. There are few opportunities to go shopping, to take part in social activities, or learn new work skills. It is a limiting environment, and leaves little room for individuals to learn to take increasing responsibility for meeting daily living needs.

De-Institutionalization

In the 1960s, after 100 years of caring for people labeled "developmentally disabled" or "mentally ill" in large state-operated institutions, the Michigan Department of Mental Health began the process of "de-institutionalization." **People formerly housed in large institutions away from public view were returned to their communities where they could live cooperatively, grow and achieve independence.**

This process is called "**De-Institutionalization.**" This was the result of many forces, including the civil rights and women's movements, and public pressure for change. Now, we assist people to learn new skills and work toward achieving independence. When individuals learn enough daily living skills to live independently, the goal is to integrate them into the community in which they live.

Finding Alternatives

Every effort is made to find alternatives to admitting people to institutions. Many people you will work with in the community lived a large part of their lives in these institutions. Others were in that setting for a short time. Others still may spend short stays in hospitals, but most of the time, they have lived in some alternative care option. Community residential settings are one form of alternative care. Michigan's Mental Health Code says if appropriate alternatives are available, a person may not be admitted to an institution.

Care must be given in the least restrictive environment possible. Community-based services are an important alternative.

Community Residential Settings

In community residential settings, people choose how they want to live, learn, and grow. Their homes are not just places to eat and sleep. How successful the home you work in is depends on your ability to provide an "everyday" atmosphere, so those living there learn the skills they need for day-to-day living. Sometimes staff falsely believe that they know what's best for the individual. In your role as direct care staff, you need to consider individual wants and needs. The fact that your paid job takes place in their home can make it difficult to balance individual needs for "home" space, with the need to learn new skills and positive ways to live cooperatively with others.

To achieve active treatment, staff must work to support people in achieving individual goals in their "Individual Plan of Service". Staff are encouraged to always think about ways to help individuals learn new social and living skills. Individuals are encouraged to take care of their own home, dress and groom themselves, and take charge of their lives. Active treatment teaches skills formally during structured teaching periods, and informally when opportunities arise.

Active Treatment has two main goals:

- **To increase the individual's control over his/her environment.**

Each person is encouraged to increase control over his/her daily living situation by learning new skills and behaviors. This may mean making choices in shopping for, preparing and eating meals. It may include choosing one's clothing, and deciding to dress alike or different from others.

- **To build on a person's strengths and abilities.**

When selecting program goals, choose those that build on a person's strengths and abilities. How we see people shapes how we and others treat them. Emphasize how the people living in the community are like you, rather than how they are different from you.

The two main goals of community settings are:

- **To increase a person's control over his/her environment;**
- **To build on a person's strengths and abilities.**

Believing Individuals Can Learn and Grow

If you know and believe people with special needs can and will learn and grow, your program will succeed. If you believe that growth is unlikely or impossible, you will not provide opportunities to learn or grow. For example, suppose you don't believe a person can learn to use "Dial-A-Ride." Instead of teaching that person how to travel on his/her own, you drive him/her to every appointment. The individual does not learn to use "Dial-A-Ride", and your expectation is fulfilled. That doesn't mean the person can't learn to use "Dial-A-Ride." It means no one believes the individual can learn this skill, so the person has not been given the opportunity to learn to travel on his/her own.

If you believe an individual diagnosed with mental illness will never change or get better, the support you offer this person will be based on this belief. Instead of giving him/her reassurance and hope for change, you may offer only pity. He/she will not receive healthy modeling from you. This does not mean that he/she cannot change, learn and grow. It simply means learning opportunities have not been presented.

How you view the people you teach and assist - your beliefs, values and attitudes about them as people -- affects their progress in learning new skills and behaviors.

How Expectations Can Turn Into Stereotypes

Expectations can turn into stereotypes. Many terms are attached to the labels "developmentally disabled", "mentally retarded", or "mentally ill." Most are negative and some contradict each other. If we think of a person as inferior, we associate qualities we dislike with that person and treat him/her negatively. It is important to mix people with special learning needs with "normal" people of the same age for learning, work, and play experiences.

The world around us provides new chances to learn, grow and acquire social skills. People removed from their families and normal school or work environments are still expected to know what to do in many situations. But institutions didn't provide chances for people to learn or try out new behaviors. Instead, those individuals learned how to live in an institution. They learned to stand in lines and wait. They did not learn to make decisions about their lives. They did not learn the independent living skills that would allow them to live on their own. The worst part of institutionalization is the attitude people have about individuals kept apart or segregated. Segregation causes the average person to believe that there must be something wrong with the person, and that segregation is required.

Segregated settings reinforce the false notion that those who *are* segregated *need to be* segregated.

When possible, work, classes, exercise or socializing should take place in adult education programs, city recreation centers, or community and senior citizen centers, rather than in special program settings where only individuals with some type of mental and/or physical impairment are present.

Why Community Integration Is Important

Residential services should integrate persons into the community. The more severe the person's disability is, the more the person needs to live in an integrated setting. There are two reasons:

- **First, the individual needs role models to see how others perform daily living activities and live cooperatively with others. As the individual sees others living successfully, those behaviors of daily living and emotional expression will be modeled.**
- **Second, differences in a person tend to set that person apart from others. If two people who have mental illness and/or developmental disabilities live together, they blend into a neighborhood. But if 12 people with disabilities live in a neighborhood, their differences are more noticeable. By living in a community neighborhood, an individual learns to develop a better personal opinion, and has a greater likelihood of learning new skills and behaviors, and contributing to the community in which he/she resides.**

HOW VALUES, ATTITUDES & BELIEFS INFLUENCE SERVICES

► At the end of this part, you will be able to:

- Recognize two of Wolfensberger's views of developmental disabilities;
- For each view, recognize at least two characteristics of the corresponding service model;
- Recognize that values, attitudes, and beliefs directly affect how we provide services.

Self-Fulfilling Prophecies

The values, attitudes, beliefs, and expectations of a person or group toward another group strongly influence the actions of and opportunities available to that group. This is called the "self-fulfilling prophecy." The earlier example about not teaching a person to use "Dial-A-Ride" shows self-fulfilling prophecy in action. It can be very simple. A child wants to do something. You say: "I don't think you can." The child believes you, so he/she doesn't try. Because the person doesn't try, the individual doesn't learn and can't do the task. You say to yourself later: "I was right. She can't do the task."

"Self-fulfilling prophecy" means if we *think* a person will behave in a certain way, we do or say things (sometimes without knowing it) that makes it likely that the person *will* behave that way. Thus, your own expectations of others are confirmed, or "self-fulfilling."

Society has many negative beliefs about individuals with mental illness. As a direct care worker, it is important for you to look at your own beliefs about individuals with special needs. Here are some facts about individuals with mental illness:

- Many individuals with mental health problems cope and live with their disorders in a positive way and live productively in society.
- Many individuals with mental health problems, with positive support, recover from their disorder.
- Most individuals with mental health problems are capable of learning to take care of themselves and their disorders.

Wolf Wolfensberger wrote that the attitudes, beliefs, and values of those who design and run community settings affects the living space within the community, and how individuals receive services. He found seven sets of beliefs, which he called Models, about people with developmental disabilities, and described the characteristics of both models. Many of the same attitudes, values and beliefs are also held about people who have mental illness. These attitudes, beliefs and values are reflected in how residential settings are run. Two of these models - ***Model I (institutions of the past)*** and ***Model VII (community settings of today)***, show the contrast in attitudes. They are summarized in the charts to follow:

Model I: The Sickness Model

Views About People With Developmental Disabilities:

- Person is perceived as having a sickness.
- Person is identified as having a disease that must have a diagnosis and prognosis.

Characteristics of the Community Setting:

- Institutions administered by medical hierarchy as a (Doctor usually serves as Superintendent);
- Institutions called state hospitals or schools;
- Living units called nursing units or wards;
 - People living in the institutions are called patients;
 - Case records are called charts;
 - Staff wear uniforms with nameplates;
 - Behavior problems are controlled physically and medically;
 - Hospital routines are followed.

Model VII: The Developmental Model

Views About People With Developmental Disabilities

- People are seen as developing individuals.
- Individuals are not seen as different or deviant. This model tries to minimize, or make up for an individual's differences. People are seen as like, not unlike others.

Characteristics of the Community Setting

- Buildings designed to -
 - 1) encourage interaction between the people who live in the home;
 - 2) foster individuality, dignity, privacy and personal responsibility;
 - 3) provide living conditions that encourage people to live successfully.
- Home-like design and family-type environment.
- Family dining rooms and regular size windows.
- Bedrooms for 1-2 people.
- Curtains or doors for baths or showers.
- Toilets designed for private use.
- Access to "risk."

Because you have a responsibility for helping others change, you must be sure your personal values, attitudes, beliefs, and expectations do **not** work against the person's progress of those with whom you are working.

What you believe, think and feel about what someone can or can't do affects the person even more when the person depends on you to learn new skills and behaviors. Our goal: support people with developmental disabilities so they can reach their full potential.

FLEXIBILITY

- ▶ **At the end of this part, you should be able to:**
 - **Define flexibility as it affects your role as a direct care staff person.**
 - **List the different roles of direct care staff.**

Flexibility

Flexibility is defined as the ability to bend, twist, and be limber. This definition also seems to describe your role as a direct care staff.

Flexibility In Your Roles As Direct Care Staff

Why do you need to be flexible? You will fulfill many roles as a direct care staff person. You will need to be physically agile, and adaptable to changing teaching programs and behaviors of those individuals you are working with. Your role is to help them learn new skills and daily living behaviors.

To accomplish that goal, your roles will include:

- Teacher of:
 - Household Skills
 - Daily Living Skills
 - Independent Living Skills
- Encourager
- Supporter

- Role Model
- Advocate
- Coach
- Intervener
- Negotiator
- Housekeeper
- Medication Administrator
- Food Assistant
- Health Care Assistant
- Good Neighbor
- You may be assigned "other" duties by your supervisor

What do all these roles mean to you? How can you be so many different people at one time? What abilities will it take to do these roles? These questions need to be discussed for you to be successful in your responsibilities as a direct care staff person.

CHOICES

- ▶ **At the end of this part, you should be able to:**
- **Recognize that all individuals share the right to choose lifestyles, friends, and careers;**
- **Recognize roles direct care staff may assume in providing choices to individuals living in a community residential setting.**

Preserving Values

As people grow mentally and physically, they meet new people and learn new behaviors and skills. We learn from and choose a lifestyle from these experiences. As we learn more, we may change how we want to live. Even so, some values and desires are important to everyone, including:

- dignity, justice, honor and freedom;
- love, a life-sharing family, a home, and being treated as someone special;
- money, good health and the benefits of modern technology;
- the chance to grow, learn, work, rest, play, eat, make individual choices, and feel good about life;
- peace and quiet when needed;
- the power to improve oneself and one's environment;
- the right to try new activities, even if what we try is not completely successful.

People cannot make good choices without experiences. How can a person decide that he/she wants to move out of one residential setting and live alone if he/she hasn't tried it? Direct care staff have many opportunities to assist people. You help them build experiences, so they

know the importance of choice. You help by making experiences and choices meaningful. You do this by making sure people have choices related to the areas outlined above.

Providing meaningful choices may be the most important thing you can do to teach independence.

Differences Between Routines and Consistency

Providing choices requires **flexibility**. Be ready to switch from one role to another. Avoid getting so comfortable with the way you do something that you force others to do things the same way. There is a difference between routines and consistency. A **routine** is a repeated behavior that is almost a habit, and is often done with no thought as to why. If you ask someone why they are doing something a certain way and the answer is: "We've always done it this way," then this is a behavior based on a routine. It doesn't mean the activity has to be done that way. People follow routines for convenience. People follow routines because they are told to, or because they never thought of another way. Routines get boring.

Consistency is repeated behavior for a reason. Consistency is needed to teach people new skills and behaviors. Some programs must be carried out, step-by-step, the way the program is written, or the program won't work.

If you ask why you are to do something in a certain way and the answer is: "We need to do it this way to help Ralph learn to tie his shoes," then this is a behavior based on consistency. Routines allow no choices. Consistency may allow choices and variations in the way things are done if you keep the goal to be achieved in mind. You must know exactly where consistency is needed to teach new skills or behaviors. Providing meaningful choices and experiences, and being consistent in the individual's treatment program maximizes an individual's chance of becoming independent.

CHANGE

- ▶ **At the end of this part, you should be able to:**
 - **Identify common reactions to change;**
 - **Identify ways to help people learn new skills;**
 - **State three possible changes facing the mental health system.**

All mental health programs try to bring about behavior change. Some people who receive services are learning or re-learning to care for themselves. Others are learning to interact with people, or to deal with their thoughts and feelings. Staff need to support people in achieving their individual goals. To do this, you must understand the change process.

How People React to Change

What thoughts and feelings might you have if:

- Your doctor said you must drop 20 pounds and keep it off?
- Your boss told you to change shifts with no notice and you have small children?
- Your friend asked you to stop smoking and you know you should?
- You were forced to get rid of your car and rely on public transportation?
- Your home was condemned and you had to move?

We all react to change in our own way, but here are some common reactions:

- We may deny that there is any reason to change.
- We think of many reasons not to change and only a few reasons to change.
- We agree that we should change, but can't seem to make ourselves make changes.
- We try to change, but find obstacles.

Feeling OK About Making Changes

We are more apt to try or feel OK about change if we can do it our way. In other words: "Help me see where I need to change, but don't tell me every step to take." Recall a situation where you wanted or needed to learn something new, or to change the way you did something. Was it fun and exciting, or scary and threatening? Was it easy or hard? Did you "go it alone" or become part of a group? Did you get help and encouragement, or did someone say: "You're stupid", or "You're doing it wrong?" These principles about how we learn new things apply to all of us:

People do learn and change. To help a person make changes, it is important to:

- **Help the person see how the change will affect him/her;**
- **Provide chance to practice change in a "low risk" setting;**
- **Be patient;**
- **Communicate that it is OK to make mistakes;**
- **Give regular feedback and encouragement;**
- **Give the person room to change in his/her own way and at his/her own pace.**

Changes Facing the Mental Health System

Systems follow the same rules and face the same problems individuals face. Within the next few years, you are likely to hear people talk about these and other changes which may affect your work and the lives of the people you work with.

Will institutions always exist? Many people feel that institutions may not be needed.

Communities have hospitals with mental health units and residential settings. A number of the institutions have already closed. As hospital stays get even shorter, and we learn more about how to help people in the community, the end of institutions may be near.

Will separate schools, day programs, and sheltered workshops continue forever?

Separate settings are far from perfect, even though people have been trying to improve these settings for years. Special help could reach people in community settings, rather than special settings. In the future, we may only support people in small community residential settings.

Will residential settings always include six people? Some will try to keep six people in every setting, but each person has special needs and should be looked at individually. Not everyone does well living with five other people. New programs may help people rent or buy their own home, and hire others to assist them in learning to live independently. If people bought or rented with part of their own funds, agencies wouldn't have to spend money on buildings and repairs. Some money might pay for support staff. While the things people need to learn would remain the same, the way you do your job would change.

If you thought the answer to any of these questions was "YES", then change may be hard for you. The answer to these questions is "NO." Look closely at your attitude. It can greatly affect how you act with people you are helping in learning new skills and behaviors. Change will be a constant in providing direct care to individuals who are mentally and/or physically disabled. Change should be viewed as an opportunity, not an obstacle.

Changes will continue to come for all of us. Be ready for them and think of these changes as opportunities, not as obstacles.

WHAT ARE MENTAL DISORDERS & DEVELOPMENTAL DISABILITIES?

- ▶ **At the end of this part, you will be able to:**
 - **Define mental illness and serious mental illness;**
 - **Name three myths about mental illness;**
 - **Recognize three types of mental disorders;**
 - **State the conditions under which a person who has been diagnosed as mentally ill might receive in-patient treatment;**
 - **Define mental retardation and developmental disabilities;**
 - **Define cerebral palsy, epilepsy, and autism;**
 - **Give three causes of mental retardation;**
 - **Name the lifetime conditions categorized as developmental disabilities.**

Mental Health

Emotional health is a relative state. There is no sharp division between being mentally well and mentally ill. People do not cross a magic line.

Mental health is a range of behaviors, thoughts and emotions.

THE PERSON THAT IS MENTALLY HEALTHY

Relationship With Self

- Knows he/she has a sense of identity.
- Accepts self, with both strengths and weaknesses.
- Respects and values self and others.
- Meets own needs and can postpone getting them met.
- Sets short and long-term goals and moves toward reaching them.
- Uses past experiences to see the present and plan for the future.
- Resolves conflicts positively.
- Shows a willingness to grow as change occurs.
- Has a strong sense of equality about self and others.
- Has an optimistic attitude toward the future.
- Has the ability to be flexible when change does occur.
- Can start and maintain positive relationships with others.
- Respects others' beliefs, values and attitudes.
- Has a clear set of boundaries about self and others.

Relationship With Environment

- Controls or changes things around him or her to meet needs.
- Adapts to change.

The person that is mentally healthy likes, respects and accepts themselves for what they are. They admit their limits and work toward positive change.

Definition of Mental Illness

The Michigan Mental Health Code defines mental illness as "a substantial disorder of thought or mood which significantly impairs judgment, behavior, capacity to recognize reality, or the ability to cope with the ordinary demands of life." For a mental or emotional problem to be a mental illness, it has to be a **major** problem that **greatly** interferes with the person's ability to function in life.

Even for people who need hospital care, the outlook is hopeful. A 1992 survey of general hospitals that offer psychiatric care showed an average length of stay of 13 days. Stays in state psychiatric hospitals are often longer, but active treatment programs and support services in the community are helping to shorten the length of hospital stays.

Some forms of mental illness seem to disappear, with long periods when an individual experiences no problems. This is called "remission." A person's ability to remain outside the hospital and stay well depends on many things, including follow-up care, and understanding and acceptance from family, neighbors, friends, and workers.

Definition of Serious Mental Illness

According to the Center for Mental Health Services (CMHS), adults with a serious mental illness are persons:

- age 18 and over;
- who currently, or during the past year, have been diagnosed with a mental, behavioral, or emotional disorder of sufficient duration to meet diagnostic criteria specified within the Diagnostic Statistical Manual of Mental Disorders (DSM-IV); and

- that has resulted in functional impairment which substantially interferes with, or limits one or more major life activities.

Three Myths About Mental Illness

- The biggest problem individuals with mental illness face as they move into the community is their illnesses. **FALSE.** Studies by the National Institute of Mental Health indicate **the biggest problem facing individuals with a mental illness is not being accepted by others.**

- The media portrays an accurate picture of individuals with mental health disorders. **FALSE.** The media sensationalizes individuals with emotional and mental health problems. The media gives the impression of dangerous, hopeless and helpless victims. Studies do not support this image. The rate of crime among individuals with mental illness is the same as the general population. **Individuals with a mental illness do recover and lead productive lives.**

- All individuals with mental illness are the same. **FALSE.** Each individual with a mental illness is different. Each has his/her own unique personality, likes and dislikes, and special interests. **It is important to get to know each person individually.**

Types of Mental Health Disorders

People with **psychosis** see or hear things that are not real to anyone else. Psychosis is characterized by strange feelings, odd behavior and distorted reality. Some become very confused, not knowing who they are or where they are. While this is going on, the person is said to be in an **acute** phase of their illness. If that phase is severe, the person may need to be in a hospital or a very intense community program. People with a long-term psychosis that have less severe symptoms are said to be in a **chronic** phase. During this phase, which may last for long periods, some people are able to live on their own. Others benefit from living in a less intensive community setting.

Schizophrenia is a common form of psychosis that affects as many as four million people in the U.S. Symptoms can include believing things that are obviously false, seeing or hearing things which do not exist, and disconnected speech.

Affective disorders, such as depression, mania, or a combination of both depression and mania, which is called **bipolar disorder**, affects eight million Americans. **Depression** is characterized by expressions of sadness, apathy, hopelessness, and the inability to experience pleasure. **Mania** includes euphoric mood, increased physical activity, and rapid continuous speech. (*A Basic Psychotherapeutics: A Programmed Text*. Spectrum Publications, 1980.)

The cause of mental illness is still unknown. One current belief is that an imbalance in brain chemistry is at least partly to blame for psychosis. For this reason, medications that correct the chemical imbalance are often used in treatment. Community residential settings that support people to set up their own homes are ways to assist those individuals toward independent living.

A person in an acute psychosis is out of touch with reality.

Anxiety Disorders occur when a person experiences unreasonable fears, tensions or anxieties of places, people, objects and other things. These disorders do not involve gross distortion of reality. Anxiety disorders affect as many as four percent of the population, and are usually characterized by unreasonable fears, tensions, or anxieties that disrupt everyday life. These disorders can take many forms, but are usually less severe than psychosis. Panic attacks, overeating, sleepwalking or constant handwashing can indicate neurosis. Some people who experience neurotic symptoms do not seek treatment. Some choose to talk over problems with a therapist. In severe cases, medication may be prescribed to help control the symptoms.

A **personality disorder** results from early childhood patterns which shape a person in certain ways. As an example - if you bent and held the top of a young tree down, the tip would turn and grow upright. Later, if you only looked at the top of the tree, you might never know anything was wrong. But there would always be a crook, or weak spot in the trunk. Personality disorders in people are like the bent tree. Some people grow up without a sense of right and wrong, or about the rights of others, or about personal property. It is very hard to undo early patterns that have become part of an individual's personality.

Treatment for these personality disorder problems is very difficult. Talking with a therapist may take years to show positive change. Medication is not always effective. What seems to help is a very structured or controlled environment you will learn about in other sections of this manual. People living in community residential settings who have personality disorders often have behavior treatment programs. These programs do not try to change the way people think, but rather try to change an individual's actions. Our goal is to help individuals change their behavior consistently over a long period of time. By changing behavior, we hope to achieve a change in their ability to function in society.

Personality disorders cause long-term distortions in the way people think and act toward others. Persons with personality disorders have many challenges to overcome.

Definition of Developmental Disabilities

A developmental disability is a severe, long-lasting condition which:

1. Is caused by a mental or physical problem or both;
2. Becomes a problem before the person reaches 22;
3. Is likely to continue for a very long time;

4. Results in major limitations in **the ability to** -
 - a. talk or express oneself and understand and follow simple directions;
 - b. take care of oneself in daily living activities, such as dressing and going to the toilet;
 - c. learn to recognize colors, shapes, letters, words and foods;
 - d. move in a normal manner that includes walking, running, and sitting;
 - e. make decisions or do what is needed to take care of oneself;
 - f. live independently;
 - g. earn money and partially support oneself;
5. Requires special treatment for a long time, often continuing over one's lifetime.

Developmental disabilities are lifelong conditions that may be attributed to a mental or physical condition, such as mental retardation, cerebral palsy, epilepsy, or autism. One or more of these conditions may occur at the same time in a person with developmental disabilities.

Definition of Mental Retardation

Mental retardation is a condition, not a disease. Mental retardation begins very early in life, sometimes before birth. People who are mentally retarded develop skills at a slower pace, and have difficulty learning, interacting with others, and working at a task or activity. At this slower pace, they tend to quickly fall behind. This gets more noticeable as the person grows older. Emotional and physical problems can impact the activity and ability of a person who is mentally retarded.

In the past, evaluations of persons with mental retardation measured problems instead of strengths. The evaluation was sometimes more disabling than enabling, because it tended to

make others expect less from the person. Labeling a person as mentally retarded can impair one's ability to see that person as an individual with certain skills and abilities. People labeled as "mentally retarded" tend to be placed in special settings away from individuals evaluated to have normal IQs.

Mental retardation is still categorized by four IQ levels: mild, moderate, severe, and profound. Less emphasis is put on labels today. These categories may not reflect how well the person is able to get along in the world. People are now classified using intellectual and social criteria. These criteria focus on strengths, so teaching programs can be individualized.

Three percent of the population is considered mentally retarded. Ten percent of us either know someone who is, or have a family member who is mentally retarded. People who are mentally retarded are like the overall population in most ways. While they develop and learn slower at a slower pace, they have the same hopes and feelings as people whose IQ levels allow them to function independently in society. The goal is to ignore labels, and help individuals with mental retardation develop to their full potential.

Causes of Mental Retardation

There are over 200 *specific* causes of mental retardation.

Many causes of mental retardation can be prevented.

Mental retardation can be caused by anything that hinders or interferes with the person's development before birth, during birth, or in early childhood years. There are more than 200 specific causes for mental retardation. However, in more than 75 percent of individual cases, the exact cause is never determined. Frequently, it is thought to result from the infant being deprived of oxygen or sugar during the pregnancy or oxygen during the birth process. Sometimes it is thought to be due to a lack of adequate food or proper care during childhood,

or other environmental factors such as exposure to toxic substances or being deprived of an opportunity to learn. Mental Retardation in these instances may be prevented or its effects reversed by changing the conditions which are thought to be the cause.

A chromosome abnormality causes one form of mental retardation - Down's Syndrome. It occurs in one out of 600 babies born, and usually results in moderate-to-severe mental retardation. Malformations of the brain or other organs, which begin during pregnancy, may also cause mental retardation. Examples include hydrocephalus (a blocking of ducts which drain excess fluid around the brain) and tuberous sclerosis (many small tumors in the brain and other tissues). Other causes of mental retardation can include Rubella (German measles) in the mother during the first three months of pregnancy, syphilis, meningitis, and Rh blood factor difference between mother and infant. Errors of metabolism (such as PKU), if not treated, can damage the nervous system and cause mental retardation. Once common, and now preventable causes of mental retardation are lead poisoning in young children, malnutrition, and inflammation of the brain during childhood measles.

Three Myths about Mental Retardation

- People who are mentally retarded are dangerous. **FALSE.** People with mental retardation are less dangerous than "normal" people.
- People who are mentally retarded need constant special care. **FALSE.** People with mental retardation may need more supervision and assistance, but very few require constant care.
- People who are severely retarded cannot learn. **FALSE.** The biggest problem is our limited ability to teach the skills needed for these individuals to function at their maximum potential.

Definition of Cerebral Palsy

Cerebral palsy is a disorder of movement and posture. Cerebral refers to brain, and palsy refers to lack of muscle control. There are five types of cerebral palsy:

- Spastic - tense and contracted muscles (most common type)
- Athetoid - constant, uncontrolled motion of limbs, head and eyes
- Ataxic - lack of balance
- Rigidity - tight muscles that resist movement
- Tremor - uncontrollable shaking

Definition of Epilepsy:

Epilepsy is a condition where there are sudden, brief changes in how the brain works. These changes affect a person's consciousness, movements or actions for a short time. These episodes are called seizures.

Definition of Autism

Autism is a disturbance in the rate and course of development. Autism affects a person's ability to relate to other people and to develop speech language. Childish rhythms of speech, understanding ideas, and using words without attaching the usual meaning are common symptoms of autism. It is also a condition where the individual has different responses to sensations, people and objects than most people. People with autism, like people with other developmental disabilities, show a wide range of scores on intelligence tests, from mental retardation to genius.

THE I-TEAM & THE PLAN OF SERVICE

- ▶ At the end of this part, you should be able to:
- Identify the function of the Interdisciplinary Team (I-Team);
- Identify possible members of the Interdisciplinary Team;
- Recognize roles and responsibilities for each member of the Interdisciplinary Team; and
- Identify the purpose of the Plan of Service.

The Individual Plan of Service

You will work with, and be a member of, an Interdisciplinary Team or "I-Team." The I-Team's task is to develop, monitor, and revise a written plan for each person. The written plan spells out all the services individuals in the community setting will receive. The plan details goals and objectives, outlines steps of progress, and states intended results. The I-Team regularly changes and updates individual plans according to individual needs.

Agencies use different names for the written plan:

Individualized Plan of Service (IPS)	A plan of action for each person, geared to specific needs, which changes as the person's skills, behaviors, and needs change.
Individualized Program Plan (IPP)	
Individualized Treatment Plan (ITP)	

The major function of the *I-Team* is to develop, monitor, and revise an individualized treatment plan for each person.

Each goal is broken into specific objectives. Objectives include desired skills and behaviors to measure how close the person is to meeting their individual goals. After the objectives are written, the I-Team decides how to help the person reach their individual goals and objectives.

For example, the goal of riding the bus alone might have a specific objective - "gets on the bus without being reminded five times out of seven." The plan should say who is to help the person reach that objective, and time frames should be set. The entire I-Team signs and dates the plan. The case manager or social worker reviews the plan and each objective at least once each month. They will be reviewing plans to see:

- Have individual objectives been reached?
- Has progress been made in learning new skills and behaviors?
- If there has been a lack of progress, is the program still OK, or does the team need to discuss changes in an individual's program?

The plan is carried out through the combined efforts of you, your co-workers and supervisor, the person being served, the case manager, and resource persons on the I-Team. Who is on the I-Team and how you contact them varies according to the person's need and the local Community Mental Health (CMH) structure. If you aren't sure how to carry out the plan or have difficulty doing making the plan work, ask I-Team members for help. Your supervisor knows how to contact those individuals.

The Plan of Service is an individualized plan for helping individuals reach their goals and objectives.

I - Team Membership

The I-Team should include the following:

- Individual being served
- Family or Guardian
- Direct Care (Residential Community) Staff
- Either a Physician or a Psychiatrist, or both, to review the plan

And others, including:

- Registered Nurse
- Certified Social Worker or Case Manager
- Licensed Psychologist
- Recreational, Occupational, and/or Vocational Therapist
- Speech Therapist
- School or work personnel
- Others as designated.

Roles and Responsibilities of Team Members

- **Individual being served** - person for which service plan is written. Informs team what he/she wants and needs.
- **Direct Care Staff** - provide direct observations about the person. They help inform the team: how the person functions, what progress he/she has made, and what logical next steps might be. Because of their ongoing contact with the person, they are essential for a complete review of the person's needs and progress.
- **Physician/Psychiatrist** - Interprets medical conditions, discusses medications, gives opinion regarding suitability of plans and medical services.
- **Registered Nurse** - Gives expert knowledge in the health area. Nurses prepare health care plans for each person and review, evaluate, and change these plans when needed.
- **Licensed Psychologist** - Writes a psychological evaluation which reviews tests given, the results and diagnoses, and recommended treatment. Writes programs to change behavior.
- **Certified Social Worker/Case Manager** - Writes a social evaluation including the person's history, family relationships, social skills, time in hospitals, institutions and other community settings. Makes plans that move people to less restrictive settings.
- **Occupational, Recreational, or Vocational Therapists**
 - a. *An Occupational Therapist* evaluates fine motor skills, self-care skills (hygiene and grooming), sensory awareness, and daily living activities.

- b. *A Recreational Therapist* assesses social skills, participation, and interest in recreational activities.
- c. *A Vocational Therapist* gives work-related evaluations to people who may be ready for training or referral.

You need teamwork to provide quality services. I-Team members are resources to you in helping individuals accomplish their goals and objectives.

ACTIVE TREATMENT

► At the end of this part, you should be able to:

- Define active treatment.
- Give three reasons why you should provide active treatment.
- State the conditions necessary to promote "a climate for growth."

What You Do Makes a Difference

As a staff person, you greatly influence what people do, and what they learn in new skills and behaviors. Your job is to encourage and support. You are clearly an important part of each person's life. You are there to help people learn to care for themselves and their home. If you believe it can be done and do your job well, the person you are teaching will become independent. This is the basis for **Active Treatment**. How do you start and maintain an environment in the community that will really help individuals develop to their full potential, and possibly lead to independence? This part of the section shows how you can carry out Active Treatment techniques.

Active treatment means watching for and using every chance to teach people new skills and behaviors that can allow them to take control of their lives and lead to independence.

Active Treatment

Some staff see people with disabilities who live in our communities as needing care and having things done for them. With that attitude, their jobs become **doing things** for people. This is like the old *Model I* way of working with people. **Staff who provide Active Treatment reflect Model VII attitudes and values.** They see people with disabilities who live in our communities as individuals working to become more independent and making decisions about their lives. Their jobs become teaching and assisting. Staff with *Model I* attitudes would wash a person's hands. **With the attitude of assisting (Model VII),** staff might help the person put soap on his or her hands and let the person do the rest. When you assist people in living their own lives, you become a "teacher", not a "caretaker". **You help people become more independent so they can make decisions about their lives. You provide Active Treatment.**

To make sure that people with disabilities who live in our communities participate in Active Treatment, their Individualized Program Plan (IPP) or Individualized Plan of Service (IPS) is written to include each person's wants and needs. This plan (a right under the Michigan Mental Health Code) applies throughout the day, and includes every place the person goes: work, home, school, the park, or a restaurant. It is the combined effort of everyone assigned to help that individual. They form an Interdisciplinary Team or "I-Team." The name comes from the many different professions or "disciplines" of the people serving on the team. We will focus on the five main parts of the Active Treatment Cycle and the role you, as a direct care staff, have in carrying out Active Treatment Plans.

The I-Team is a group of individuals with different responsibilities who are assigned to help individuals with disabilities in a community or alternative setting. The I-Team assists those individuals in developing a plan to meet individual needs.

MAIN ELEMENTS OF ACTIVE TREATMENT:

Assess

As the member of the I-Team with the most direct individual contact, you have a very important role in the fact-finding stage. You discuss the strengths, skills, preferences and needs of each person who lives in your home. While others may have test results and IQ scores, you know and have recorded what the person actually does or doesn't do in the community setting. For the team to develop a plan that works, all the person's skills, or lack of skills need to be noted and discussed. Your knowledge is vital.

Plan

From all this information, the I-Team sets goals to guide the planning process. Once the goals have been established, a plan is developed to encourage an individual's participation and independence. The plan of service is the game plan on how everyone will go about providing the support to make sure goals and objectives of the plan are met.

Do

The plan is a written so it can be done by anyone reading the plan, and in the way the plan describes. You, the direct care staff, are the "doers." You have to be ready to act whenever and wherever needs or opportunities come up. Sometimes the most important needs come at odd times, like 6:30 a.m. or 8:45 p.m. No matter what time or what place, the plan needs to be carried out. Don't wait for a structured teaching time to use the plan. Look at every opportunity as a "teachable time" - the moment you feel the person is best able to learn or practice a new skill or behavior.

Evaluate

Some plans work well from the start. Others need changes. The only way for the **I-Team** to know which parts of a plan work and which do not is *for you to record what and how well the individual performs activities included in their Plan of Service*. The case manager evaluates monthly what you record, so the I-Team can see how the plan is going. Plans work better on some days than others. The team knows that. An individual's activities, successful or less than successful, need to be recorded for evaluation. Accurate information is vital. Always record exactly what happens when you carry out the plan.

Change

We constantly need to change plans to better meet the goals of each individual. An accurate record of an individual's activities helps the team evaluate and "fine tune" the plan for each person. Programs and activities may be changed if goals are met. New ideas can be added to better meet needs, to work on new goals, to remove boredom or to take an individual's preference into account. Changes make the plan more interesting for you and for the person you are working with.

DOCUMENTATION

► At the end of this part, you should be able to:

- Identify the purposes of documentation;
- Identify items included in the person's record;
- Recognize things to do and not to do when writing in the record; and
- Recognize that the individual's record is a legal document.

Documentation is another way to communicate with others. Each home must have a recordkeeping system. As an I-Team member, *you* will be recording a person's progress or lack of progress in the individual's record.

The method of recordkeeping may vary, but all individual records must:

- note changes in the plan;
- note changes in the person's health;
- describe unusual events involving the person;
- give details about any illness; and
- list unplanned physical interventions.

The record is a legal document specified by the Michigan Mental Health Code. As a legal document, all information in the record must be kept confidential (private), and may be revealed only under strict conditions. For example, it can be subpoenaed by the court. The record states why the person is in the community setting, services needed and provided, and the progress, or lack of progress toward plan goals.

The individual's record is a *legal document*. It tells:

- **why the person is in the community setting;**
- **services needed and provided;**
- **progress or lack of progress;**
- **any changes in the person's status;**
- **all unusual behavior or events;**
- **actions and activities of staff working with the individual.**

Items included in the record are:

- identifying features of the person;
- past and present treatment of physical and psychological conditions;
- social and family history;
- doctor's orders for medication and treatment;
- psychological evaluations; and
- progress notes.

Agencies such as the Department of Public Health or the Department of Social Services that regulate and license, mandate certain recordkeeping practices. Agencies that pay for service, such as Medicare or Blue Cross, also require accurate records. The record collects data for these agencies and all staff who work with the person. It is **vital** for health care and holds the plan of service for each individual. Specific goals and responsibilities of team members are also stated in the record.

The record is a communications tool. It is also a resource for data collection about an individual's health and their progress toward achieving individual goals and objectives.

Documenting in the Individual's Record

Do -

- Describe events in the order in which they occurred.
- Use only approved abbreviations or write out the word.
- Draw a line through errors. Above the error, write "error," your initials, and the date.
- Sign your first and last name and your title, if you have one.
- Draw a line through any unused space between the end of your comments and your signature, so that what you have written cannot be changed.
- Do use the person's legal name.

Don't -

- Don't erase or blot out errors.
- Don't use nicknames; use the person's legal name.
- Don't postpone documenting. Document daily in the individual's record.
- Don't leave a space for someone else who did not have time to document.
- Don't use unapproved abbreviations.
- Don't change any record for any reason.
- Don't use one person's full name in another person's record. Use initials or first name.
- Don't falsify an individual's record.

Your observations in the record are essential, and will be used to develop a successful plan with the individual being served.

PROVIDING A CLIMATE FOR GROWTH

Value and Respect Others

Were you ever treated like you were stupid or "in the way?" It hurts. What we learn from such situations is to avoid being with people who show that kind of attitude. The people living in a community setting can't avoid being with you. You can help the individuals under your care feel valued and respected. Listen to them. Ask for their thoughts, feelings and ideas. Tell them when they do well. Let them know that it is OK to make mistakes. **If people feel good about what they are doing, they'll keep making progress.**

Involve people in the decisions that affect them. Provide opportunities for meaningful choices. Make sure they attend their own I-Team meeting.

Provide a Supportive Atmosphere

When we decide to behave in a different way, our first attempts are critical. If our first tries bring laughter, ridicule, or anger, we aren't likely to try again. The "real world" is often hard on people trying new things. It is important to have a place to practice where the results aren't criticized and where "just trying" may be rewarded. Individuals need feedback to help shape and improve their efforts. Individuals need to experience success. They need to be told in a caring way how to improve in doing an activity.

When we take chances, try new things and get support for doing so, trust develops. As trust develops, individuals are likely to try more new things. The more individuals try, the more they learn. If individuals don't get support and don't develop trust, they seldom try new behaviors. The risks are too great. The harsh results are too hard to live with. Clearly, people need support and encouragement to try new behaviors. A community setting provides many choices in a protective setting. Then, when people become somewhat skilled and confident, they can make choices and try new skills and behaviors in the "real world."

To help people learn new skills and behaviors, provide plenty of encouragement, helpful hints and provide opportunities for success and praise. Be consistent and positive.

Be a Role Model

Whether we realize it or not, we learn many things by watching and imitating other people. People see and hear you do and say a variety of things. They likely see you as a role model and try to behave in the same ways you behave. This is even more true if they like, trust, and respect you. That makes it very important for you to always be aware of what your behavior.

You are a role model. Help others grow by modeling desirable behavior.

Help People Take Small Steps That Make Sense

All people have strengths, assets, and abilities. We all have things that we cannot do at all or do well. Keep in mind an individual's strengths, as well as areas where an individual can improve. When you see needs, set realistic and practical goals.

A car doesn't jump from 0 to 60 miles an hour. It accelerates gradually to reach the desired speed. And each car accelerates at a different rate. This same idea applies to setting goals.

The person and the I-Team may agree that table manners need to be improved. We can't expect instant improvement. The person won't follow *Amy Vanderbilt's Rules of Etiquette* the next week! When we break long or complex lessons into small parts, each lesson becomes easier to learn, and our chance of success greatly improves for learning new skills or behaviors.

Active treatment means you don't always have to wait for a structured time to teach a new skill. Most learning happens *informally*, or by accident. Teach when the opportunity arises. For example, a plan requires daily stretching movement of a person's arm to "increase range of motion." You could move the person's arm up and down, or ask the individual to reach for a hook to hang up his/ her coat. Hanging a coat teaches independence and increases range of motion at the same time. While that is only one opportunity to stretch, look for others.

It takes time for people to master and improve new skills, or to stop bad habits or "inappropriate behavior." We help speed the process by supporting the person's efforts. We reward small successes, and make sure the environment stimulates and meets the needs of the person. This can be difficult when working with people who are used to having things done for them, as in the Model I setting. These settings provided little stimulation and many people learned to look at the world with total lack of interest.

Create many opportunities for success. Set realistic and practical goals. Break an activity into small steps.

Involve as many senses as possible - touch, taste, smell, sight and hearing.

RESOURCE MATERIALS

Some content in this section has been adapted from the following resource materials:

AAMD: Manual on Terminology and Classification.

"A Working Paper: Basic Orientation to Mental Retardation", Jerry Leismer.

"Facts of Mental Retardation", National Association for Retarded Citizens, 2709 Avenue East,
P.O. Box 6109, Arlington, TX 76011.

Michigan Department of Mental Health, Michigan Mental Health Code. *"Definitions of
Mental Retardation, Developmental Disabilities, and Mental Illness."*

Michigan Department of Mental Health. *"Module 1."* DMH Group Home Curriculum.,
Office of Resource Development. Lansing: 1984.

"Rights Folio." *Way To Go Series.* Baltimore: University Park Press, 1978.

"What is Mental Illness?"; National Clearinghouse for Mental Health Information;
National Institute for Mental Health, 1971.