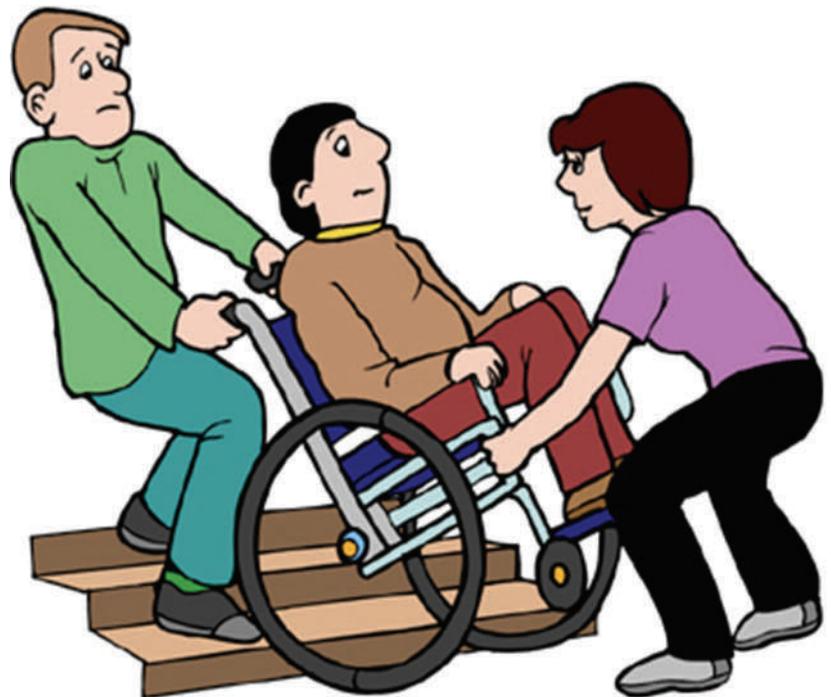


A HANDBOOK FOR CLINICIANS

PRIME HOME HEALTH SERVICES

QUALITY MANAGEMENT DEPARTMENT

CARING FOR PATIENTS WITH SPECIAL NEEDS



A HANDBOOK FOR CLINICIANS

PRIME HOME HEALTH SERVICES

CARING FOR PATIENTS WITH SPECIAL NEEDS

Table of Content

Introduction	
Mission/Goals.....	Page 1
Overview of Mental Retardation and Developmental Disability.....	Page 2-3
Causes of MRDD.....	Page 4
Classification of Mental Retardation and Developmental Disability.....	Page 5
Types of Diagnosis Associated with MRDD.....	Page 6-11
Caring for Patients with Special Needs	
Behavioral Traits.....	Page 12
Clinician Assessment/Intervention.....	Page 13
Patient and Caregiver Education	
Case Coordination.....	Page 14
Home Health Aide Services	
Emergency Management.....	Page 15



A HANDBOOK FOR CLINICIANS

Introduction

This Manual was developed to be used by Prime Home Health Services clinicians as a resource guide for the management of patients with Mental Retardation and Development Disabilities (MRDD).

Mental Retardation and Developmental Disability (MRDD) is not a disease in itself, but can be classified as a condition that affects the intellectual and physical functioning of the individual. Prime Home Health Services recognizes this aspect of care and classifies these individuals as patients with special needs.

The agency will focus on the functional aspects of the patient's ability to manage activities of independent daily living. Prime Home Health Services is dedicated to the development and training of a team of professional and supportive staff who will utilize a multidisciplinary approach to provide care, treatment, and services to this diverse patient population.

Our multidisciplinary team of nurses, case coordinators, rehabilitation therapists, social workers and paraprofessional support staff is committed to working collaboratively to address the challenges, and to meet the needs of adult MRDD patients.

Mission

Recognizing that MRDD is not a disease, Prime Home Health Services will focus on improving the functional abilities of patients with special needs.

Our Professional staff will work with you, your physician and your family to develop and facilitate a plan that meets your special needs.

Goals

1. To provide safe, effective, and therapeutic care to adult patients with special needs.
2. To promote and maintain an interdisciplinary team approach to the care of MRDD patients.
3. To provide education to families/caregivers on coping skills and strategies to assist with the management of MRDD patients.

PRIME HOME HEALTH SERVICES

CARING FOR PATIENTS WITH SPECIAL NEEDS



A HANDBOOK FOR CLINICIANS

PRIME HOME HEALTH SERVICES

CARING FOR PATIENTS WITH SPECIAL NEEDS

Overview of MRDD

Mental Retardation and Developmental Disability (MRDD) is a condition where individuals have varying alterations in intellectual and physical functioning that restricts their ability to communicate, and perform some/or all activities of daily living.

Individuals who are mentally challenged may have problems with communication, self care management activities of daily living, social skills, interacting in the community, leisure activities, health and safety issues.

Developmental disability starts during childhood and can interfere with the normal course of development and is likely to continue indefinitely. Since 1970, the focus of the definition has shifted from the condition to the impact of the limitations on the individual's ability to function in activities of daily living.

Studies in the 1980s suggest that Mental Retardation (MR) occurs in 2%-3% of the general population in the United States. According to the 1990 census, 6.3-7.5 million people in the United States have some form of Mental Retardation.



A HANDBOOK FOR CLINICIANS

The Developmental Disabilities Assistance and Bill of Rights Act Amendment of 1987, passed by Congress, reported that there are more than two (2) million persons with developmental disabilities in the United States, and notwithstanding their severe disabilities, individuals with disabilities have capabilities, competencies and personal needs that often require specialized lifelong assistance in a coordinated manner by many community agencies.

The Congressional findings also indicated that the needs of these individuals were sometimes overlooked or not appropriately addressed by community agencies in their planning and delivery of services.

The law was amended in 1987 to ensure that assistance is provided to the State, public and private non-profit agencies and organizations to ensure that all persons with disabilities receive services and other assistance and opportunities necessary to enable such persons to achieve their maximum potential through increased independence, productivity, and integration into the community.

Amendments to the law were made in 1996 and 2000 to strengthen the rights of individuals with disabilities and to provide support for families caring for these individuals.

PRIME HOME HEALTH SERVICES

CARING FOR PATIENTS WITH SPECIAL NEEDS



A HANDBOOK FOR CLINICIANS

PRIME HOME HEALTH SERVICES

CARING FOR PATIENTS WITH SPECIAL NEEDS

Causes of MRDD

Mental retardation is a complex condition which may be caused by multiple factors such as:

- Genetic or defective genes (Down syndrome).
- Drugs, cocaine or amphetamines taken during pregnancy.
- Fetal alcohol syndrome due to excessive alcohol consumption during pregnancy.
- Environmental influences (exposure to radiation, lead or mercury during pregnancy).
- After birth problems related to lead poisoning, severe malnutrition.
- Early childhood diseases (German measles).

In about 75% of the cases, the cause is unknown. The condition may start at birth or early childhood and continue into adulthood. It is important for clinicians to understand that if the individual was identified as having normal intelligence, and becomes impaired as an adult due to severe mental illness or brain injury, this condition is not interpreted as mental retardation. Mental retardation is more common among males than females.



A HANDBOOK FOR CLINICIANS

Classification of MRDD

There are four levels of mental retardation: mild, moderate, severe and profound. This determination is based on the individual's performance on the standardized IQ test, and the ability to learn adaptive skills such as communication and social interaction.

Mild Retardation

Patients with mild retardation have an IQ score of 50 -75 and may be slow learners. They have the ability to learn practical skills, including education, social and job skills. This group of patients is able to live independently.

Moderate Retardation

These patients have an IQ score of 35 - 50. They are able to perform simple tasks with supervision. They have difficulty with speech and motor skills and cannot live alone. They live in group homes.

Severe Retardation

These patients have an IQ score of 20 - 35. Individuals in this category have delays with motor skills development, limited ability to communicate, and may experience difficulty with performing activities of daily living such as bathing, grooming and dressing. These patients live in group homes in a protected environment.

Profound Retardation

These patients have an IQ score of less than 20. Individuals in this category are considered severely mentally challenged. They are unable to perform self care and may have other medical problems and mental disorders.



A HANDBOOK FOR CLINICIANS

PRIME HOME HEALTH SERVICES

CARING FOR PATIENTS WITH SPECIAL NEEDS

Types of Diagnosis associated with MRDD

- Autism
- Birth Defects
- German measles (Rubella)
- Cerebral Palsy
- Down Syndrome
- Environmental Diseases
- Epilepsy
- Fetal Alcohol Syndrome
- Genetic Diseases
- Lead Poisoning
- Meningitis
- Muscular Dystrophy
- Thyroid Disease
- Tourette Syndrome

Autism

This is a developmental disorder that occurs in the first 3 years of life, and affects the brain's normal development of social and communication skills. The cause is unknown. Patients with autism may be overly sensitive to light, hearing, touch, smell or taste, may show unusual attachments to objects, perform repeated body movements and may have difficulty maintaining conversations.



A HANDBOOK FOR CLINICIANS

Birth Defects

Birth defects are abnormalities present at birth that cause functional or mental disability. There are two main types of birth defects: structural and functional.

Structural birth defects are related to problems with body parts which result in abnormality. Some physical defects are cleft lip or cleft palate, heart defects such as misshaped valves and neurological defects such as spina bifida.

Functional birth defects can lead to developmental disabilities including behavioral disorders, speech language difficulty, learning disabilities, blindness, deafness or movement and ambulation problems.

German Measles (Rubella)

German measles/rubella is a disease that is passed from mother to baby during pregnancy and is associated with mental retardation in infants and in rare cases death.

Cerebral Palsy

This is a neurological condition that results in mild to severe loss of muscle tone and can result in one-sided weakness, difficulty walking, writing or using utensils. These individuals require the use of assistive devices such as braces, and may have speech and swallowing problems.

PRIME HOME HEALTH SERVICES

CARING FOR PATIENTS WITH SPECIAL NEEDS



A HANDBOOK FOR CLINICIANS

PRIME HOME HEALTH SERVICES

CARING FOR PATIENTS WITH SPECIAL NEEDS

Down Syndrome

Down syndrome is also called “Trisomy 21”. This is a condition in which extra genetic material causes delays in the way a child develops both mentally and physically. Individuals with Down syndrome inherit one more chromosome beyond the total 46 chromosomes that are inherited from both parents. This extra chromosome is responsible for the physical features and developmental delays associated with Down syndrome. Individuals with this condition usually have distinctive physical features such as a flat facial profile, flat affect, an upward slant to the eyes, small ears and a protruding tongue.

Children with Down syndrome usually benefit from early intervention services and although development is slow, they can learn and even go to college and transition to semi-independent living in adulthood. They are able to hold jobs and become successful in the community.

Environmental Diseases

These diseases are caused by environmental factors that are not transmitted genetically or by infection. Environmental factors can be related to exposure to toxins, radiation, chemicals found in household cleaners, substance and drug abuse, stress, physical and mental abuse.



A HANDBOOK FOR CLINICIANS

Epilepsy

Epilepsy results from the generation of electrical discharges from the nerve cells of the cerebral cortex of the brain causing recurrent seizures. Patients with Epilepsy may stare blankly during a seizure while others may have convulsions.

In most cases the cause is unknown, but it can be associated with cerebral trauma, intra cranial infection and brain tumors. Seizures may occur during sleep or at frequent intervals during the day.

Fetal Alcohol Syndrome

This is a condition that is caused by excessive consumption of alcohol by pregnant women. The excessive alcohol impacts on the normal development of the child.

Genetic Diseases

Genetic diseases occur as a result of chromosome abnormality or mutant genes. Some genetic diseases such as Sickle cell anemia can be identified early through genetic screening of all newborn infants.

Lead Poisoning

Lead poisoning occurs when lead builds up in the body over a period of time. Children are more vulnerable than adults and it can affect the mental and physical development of children. The most common source of lead poisoning is related to lead based paint, and lead contaminated dust in older buildings.

PRIME HOME HEALTH SERVICES

CARING FOR PATIENTS WITH SPECIAL NEEDS



A HANDBOOK FOR CLINICIANS

Meningitis

Meningitis is an infection or inflammation of the membranes covering the brain or spinal cord. The most common causes in adults are from bacterial infection (streptococcus pneumonia or haemophilus influenza). The onset is usually sudden and is characterized by severe headache, stiffness of the neck, malaise, irritability, nausea and vomiting, delirium which may progress to complete disorientation. It is important that clinicians instruct patients and caregivers on the importance of vaccinations.

Muscular Dystrophy

Muscular dystrophy is a group of genetically transmitted diseases characterized by progressive atrophy of skeletal muscles. There is loss of muscle strength with increasing disability and deformity. The most common types of muscular dystrophy appear to be related to a genetic deficiency of muscle protein. There is no cure for muscular dystrophy, but medications and rehabilitation therapy can slow the progression of the disease.

Thyroid Disease

The thyroid gland is one of the endocrine glands which make hormones and play a role in metabolism and regulation of body temperature. It is located in the neck and secretes the hormone thyroxin which is essential for normal body growth in infancy and childhood.

Excessive production of thyroid hormone can lead to Graves's disease (hyperthyroidism) and plumer's disease (toxic goiter) Signs and symptoms associated with hyperthyroidism are excessive weight loss, tiredness, increased heart rate and sensitivity to heat. Diminished thyroid hormone production can lead to cretinism (Dwarfism).



A HANDBOOK FOR CLINICIANS

Tourette Syndrome

Tourette syndrome is an inherited neuropsychiatric disorder with onset in childhood, and is defined as part of a spectrum of tic disorders. The severity of the tics decreases in adolescence and the mild form is seen in the adult. Tourette syndrome is characterized by multiple physical (motor) tics and at least one vocal (phonic) tic. There is no effective medication for every case of tics, medications and therapies can help when their use is warranted.

Tics can be classified as sudden, repetitive, stereotyped movements and utterances that occur periodically. Tic movements in some cases occur as eye blinking, coughing, throat clearing, sniffing, and facial movements.

Obsessive compulsive behavior and attention deficit hyperactivity disorder are often associated with Tourette syndrome. Individuals with Tourette syndrome usually have a normal life expectancy and intelligence.



PRIME HOME HEALTH SERVICES

CARING FOR PATIENTS WITH SPECIAL NEEDS



A HANDBOOK FOR CLINICIANS

Caring for Patients with Special Needs

Patients with special needs often have varying levels of disabilities which can affect their ability to communicate, understand how to perform some tasks/activities of daily living, ambulate or live independently in the home environment.

Clinicians in the field will need to understand the broad spectrum of MRDD and some of the most common diagnosis associated with the condition. It is also important, that during the initial assessment visit, the clinician observes the patient for potential behavioral traits associated with some diagnosis, which can vary from mild to severe impulsive and self injurious behavior.

Behavioral Traits

Some of the behavioral traits that are likely to be demonstrated by special needs patients include but are not limited to:

- Low tolerance for frustration
- Aggressive behavior that may progress to self-injury
- Low self esteem
- Impulsive, stubborn and immature
- Happy and amicable
- Some patients may be easygoing, while others are aggressive
- Multiple personality characteristics
- Difficulty with communication
- Intolerance to touch, and may lack the ability to Show affection



A HANDBOOK FOR CLINICIANS

Clinician Assessment/Intervention

Providing care in the home to adults with special needs is more challenging for the clinician because of the various levels of MRDD and the behaviors associated with each level. However, it can be very rewarding because you are helping another human being to grow and reach his or her potential to the extent possible. An understanding of the behavioral traits and associated MRDD diagnosis will promote better assessments and interventions by our nurses and therapists in the home.

During the initial assessment it is important that clinicians listen sensitively in order to understand the patient and caregiver's needs, desires, current skills, interpersonal conflicts and self-esteem. The clinicians will need to assess the home environment carefully to ensure that it is adaptable and can accommodate any equipment that the patient may need to function independently.



Patient/Caregiver Education

The assigned disciplines will develop individualized care plans with the patient and family/caregivers. Clinicians should encourage the patient's family/caregivers to participate and cooperate with the plan. Patient/family/caregiver teaching by the nurses will require the use of more visual aids, since some patients may have difficulties with communication.



PRIME HOME HEALTH SERVICES

CARING FOR PATIENTS WITH SPECIAL NEEDS



A HANDBOOK FOR CLINICIANS

PRIME HOME HEALTH SERVICES

CARING FOR PATIENTS WITH SPECIAL NEEDS

Case Coordination

The Case Coordinator's role is very important in the management of patients with special needs. The Case Coordinator is responsible for ensuring that the information from the multidisciplinary team of nurses, therapists, social workers and paraprofessional workers (if applicable) is integrated and addresses the needs of the patients. The Coordinator will need to follow up with the family/caregiver to ensure that the patient is obtaining the appropriate medical services.



A HANDBOOK FOR CLINICIANS

Home Health Aide Services

Home Health Aides (HHAs) who are assigned to patients with special needs should have received the appropriate training, and will work under the direction of the nurse/therapist who will develop an appropriate plan of care for the HHA. The plan of care will specify tasks to be completed by the aide based on the needs of the patient. The HHA will be responsible primarily for providing and assisting the patient with personal care, and any functional tasks recommended by the therapists. It is also the responsibility of the aide to report any behavioral or other changes in the patient's condition to the Coordinator.



Emergency Management

Patients with special needs will require extra support and assistance during an emergency situation. The nurse should encourage the patients living alone to plan for an emergency and encourage them to have a prepared "Go Bag" that should include copies of all important documents in a waterproof bag, extra set of house keys, bottled water and energy snacks, flashlight and extra batteries, a list of all medications the patient is taking and a name of a physician, portable radio, toiletries, phone numbers of friends and family.



A HANDBOOK FOR CLINICIANS

PRIME HOME HEALTH SERVICES

CARING FOR PATIENTS WITH SPECIAL NEEDS



PRIME HOME HEALTH SERVICES LLC

**3125 Emmons Avenue
Brooklyn, NY 11235**

Tel.: 718-646-1900

Fax: 718-646-4900

www.primehomehealth.com

