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## Clients with Disabilities

A **disability** is the impairment of a physical or mental function. Disability may result from a disease, a complication of pregnancy, or an injury. A disability can be temporary or it can be permanent.

Depending on the disability, a person may not be able to perform activities of daily living (ADLs). Work and social activities may be limited. People with disabilities may be more susceptible to illness. By strictly following the care plan and carefully observing and reporting, home health aides can help clients with disabilities avoid illness. Their efforts may also help clients lead more independent lives.

A person who has a disability may find it difficult to cope with the stress a disability can cause. How well a person copes depends on different factors, including the following:

- The person's general ability to cope with stress
- The specific disability (For example, is the disability severe? Does it restrict movement and function?)
- Available support (For example, does the client have family members, friends, and others who can help? Are there community, federal, state, or religious organizations that offer support?)
- Other difficulties that exist (For example, does the client have financial troubles? Is the living environment adequate?)

Families of people with disabilities may also find it difficult to cope. Family members may feel stress, resentment, disappointment, guilt, shame, anger, or frustration. Caring for someone with a disability can be a big responsibility. It affects a family's time, energy, patience, and financial resources. Home health aides can give family members a much-needed break (Fig. 17-1).



**Fig. 17-1.** The time a home health aide spends with a client with disabilities may be the only break a family member receives.

Clients and their families may need additional support, including counseling, to help deal with the disability. The HHA should tell her

supervisor if she thinks a client or family member needs additional support.

Many clients with disabilities develop strong emotional attachments to their caregivers. Clients may also become angry with caregivers. Clients may resent being dependent or they may be afraid of efforts to encourage independence. HHAs should be patient with clients. If a client's emotions are more than an HHA can handle, she can speak to her supervisor.

### 1. Identify common causes of disabilities

There are hundreds of diseases and disorders that may cause disability. Among them are diabetes (DM), cerebrovascular accident or stroke (CVA), muscular dystrophy (*DIS-troh-fee*) (MD), congestive heart failure (CHF), acquired immunodeficiency syndrome (AIDS), chronic obstructive pulmonary disease (COPD), Parkinson's disease (PD), rheumatoid (*ROOM-a-toyd*) arthritis (RA), osteoarthritis (*ah-stee-oh-ar-THRYE-tis*) (OA), and multiple sclerosis (*skler-OH-sis*) (MS).

Disabilities are also frequently caused by accidents. Head or spinal cord injuries can cause severe disabilities, including paralysis and brain damage. Accidents can also cause vision loss, hearing loss, or a number of other disabilities.

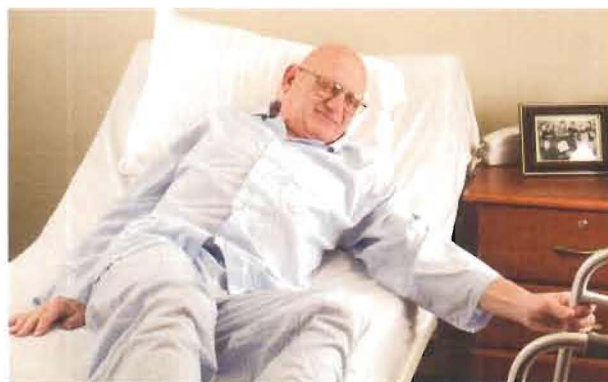
A person may be born with a disability due to a complication of pregnancy or childbirth, or because of an inherited gene. Cerebral palsy, which can cause mild to severe physical disability, can result from premature birth. Malnutrition or drug or alcohol abuse during pregnancy can cause lasting disabilities in babies. Down syndrome is a genetic abnormality that causes physical and mental disabilities.

### 2. Describe daily challenges a person with a disability may face

Which activities are challenging for a person with a disability depends on the disability. A person who has an intellectual disability will

face different challenges than a person who is not ambulatory. However, any of the following activities may pose a challenge for a person with a disability:

- Getting out of bed (Fig. 17-2)
- Preparing or eating meals
- Washing, dressing, or grooming himself
- Getting to the bathroom
- Communicating with family, friends, or caregivers
- Meeting basic human needs for acceptance, belonging, and community
- Getting from one place to another
- Finding a job or functioning in a job
- Making ends meet financially



**Fig. 17-2.** Even getting out of bed in the morning may pose a challenge for a person with a disability.

Even the most basic ADLs can be challenges for a client with a disability. The HHA can help by assisting a client with a disability to meet these challenges successfully each day.

### 3. Define terms related to disabilities and explain why they are important

The terms used to describe people with disabilities have changed. For example, it used to be common to call a person in a wheelchair a "cripple." Now most people find that term offensive. Some find even the term "disabled" offensive,



because it may imply that they are less competent than others. The HHA must be sensitive to the terms used to describe clients.

Many people with disabilities want to be viewed and described as people first, rather than identified by their disability (using person-first terminology). Thus, someone may prefer to be called “a person who is deaf” rather than “a deaf person.” Someone else may prefer the term “hearing-impaired.”

To avoid using terms that may be offensive, the HHA should find out how clients refer to their disability and use those terms. Part of providing person-centered care is honoring each client’s preferences about the language used to discuss her needs and care. Being sensitive when discussing a disability is important, and discussions about clients should only be held with the care team and, if appropriate, the family.

#### 4. Identify social and emotional needs of persons with disabilities

People with disabilities have the same social and emotional needs all human beings have. However, some disabilities make it more difficult to meet those needs. The HHA can help meet these needs when appropriate. As discussed in Chapter 8, basic psychosocial needs include the following:

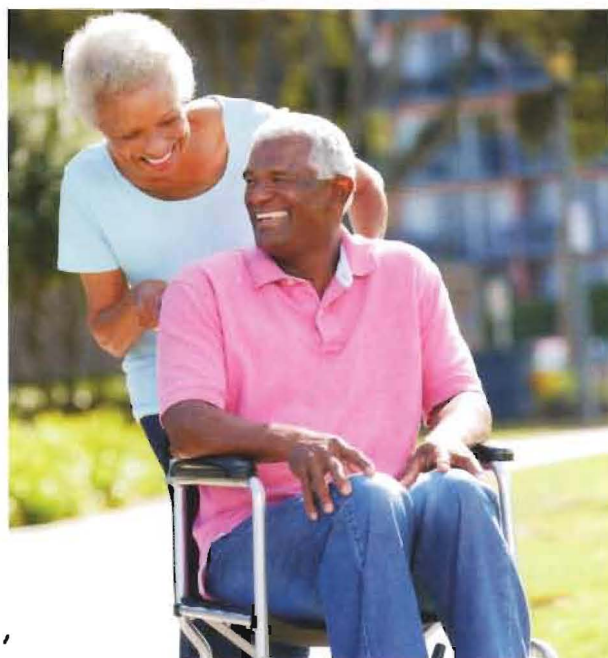
- Independence
- Dignity
- Acceptance
- Social interaction
- A sense of worth

The HHA should encourage self-care and encourage clients with disabilities to do all they can for themselves. Clients should be given opportunities to show what they can do. The HHA should not take over a task just because she can do it faster or better. The sense of independence,

dignity, acceptance, social interaction, and self-worth are all boosted when a client is able to perform a task for himself. On the other hand, a client should not be pushed beyond his abilities. Humiliation and failure do not help fulfill social or emotional needs. All clients should be treated with respect.

#### 5. Explain how a disability may affect sexuality and intimacy

Disability can affect sexual desires, needs, and abilities. Clients may be sensitive about how an illness or injury has affected their sexuality. Although sexual desire may not be lessened by a disability, the ability to meet sexual needs may be limited. Many people who use wheelchairs can have sexual and intimate relationships, though adjustments may need to be made. The HHA should not assume she knows what impact a physical disability has had on sexuality (Fig. 17-3). She should be sensitive to privacy needs and should not judge or make comments about any sexual behavior observed.



**Fig. 17-3.** Human beings continue to have sexual needs throughout their lives. Caregivers should not assume they know the impact a disability may have had on meeting sexual needs.

## 6. Identify skills that can be applied to clients with disabilities

Many of the basic skills that have already been covered or will be covered in other sections of this book apply to working with clients with disabilities:

- Communication (Chapter 4)
- Safety and body mechanics (Chapter 6)
- Safe and comfortable transfers, ambulation, and body positioning (Chapter 12)
- Assisting with ADLs (Chapter 13)
- Measuring vital signs and obtaining specimens (Chapter 14)
- Skin care (Chapter 16)
- Housekeeping and meal preparation (Chapter 21 and Chapter 23)

There are some adjustments that an HHA will need to make for each client. However, in general, working with a client who is disabled is no different than working with any client. If the HHA treats each person as an individual and with respect and provides person-centered care, she will be on her way to providing excellent care for all clients.

## 7. List five goals to work toward when assisting clients who have disabilities

When working with a client who is disabled, the HHA should do the following:

**Promote self-care and independence.** She can ask the client how much assistance she needs to perform certain tasks. The HHA should tell the client about the goals of the care plan and involve her in deciding how assigned tasks should be performed. Personal preferences should be followed (Fig. 17-4). Self-care and independence cannot be accomplished without the client.



**Fig. 17-4.** By asking a client about personal preferences, the HHA will find ways to promote dignity, independence, and self-care, which is a part of providing person-centered care.

**Assure the client's safety.** Being aware of accidents that commonly occur in the home helps prevent them. Most can be avoided if a person thinks ahead. Each client is an individual with special needs. The HHA should think critically about each client's abilities and disabilities. Safety concerns vary depending on the disability. For example, clutter on the floor can cause falls for clients with impaired vision. Checking the home each day for things that might be unsafe can help prevent accidents. Preventing problems before they occur is called being proactive. It is much better than being reactive, or reacting to an accident that has occurred. Being able to foresee problems is very important. Both the HHA and the client should use proper body mechanics to help avoid injury.

**Promote the client's health and comfort.** The HHA can help clients by maintaining nutrition and hydration and by assisting with personal care. The care plan and the assignment sheet will include instructions for this type of care. To provide further comfort, the HHA should watch and listen to the client. Thinking about how she might feel if she were in a similar situation helps the HHA better anticipate a client's needs. For example, she may notice that an extra pillow under the client's arm would help keep his shoulder from drooping. Some clients with disabilities may be unable to communicate their wishes.



**Maintain the client's dignity and self-worth.** The HHA should never discuss a client with anyone other than a member of the care team or, if appropriate, the client's immediate family (Chapter 3 contains more on client confidentiality). A client who is disabled should be treated with the same respect as any client. The HHA should try to recognize that a person with a disability may have many feelings about her situation and should be sensitive to these feelings. It is helpful to find ways to make clients feel good about themselves. Clients should be encouraged to direct how and when care is provided.

**Maintain the stability of the client's household.** Disability can disrupt the stability of a home, causing insecurity, anxiety, depression, and disorder. The HHA is in the home longer than any other member of the care team. She can help maintain the stability of the household by being punctual and dependable and by respecting the schedules of the family. The HHA should work calmly and efficiently and should act as a role model by showing acceptance and encouragement of the client.

## 8. Identify five qualities of excellent service needed by clients with disabilities

When asked what qualities they need and value most in home health workers, people with disabilities list the following:

1. **Punctuality:** Being on time for all scheduled visits makes a big difference to a client who needs assistance.
2. **Reliability:** Clients with disabilities may depend on help to meet basic needs, so being reliable is essential.
3. **Responsiveness to needs:** A client's needs may change, and the HHA should be willing (with the approval of a supervisor) to adapt service to be most helpful.

4. **Continuity:** Constantly changing caregivers may be disruptive or inconvenient for people with disabilities.
5. **Positive attitude:** An HHA's positive and encouraging attitude is important to clients with disabilities (Fig. 17-5).



**Fig. 17-5.** Being positive and encouraging is something that is expected of home health aides.

## 9. Explain how to adapt personal care procedures to meet the needs of clients with disabilities

The guidelines below will help explain the special needs clients with various disabilities may have. A home health aide's care should always be adapted to the individual client's needs. The care team works together to discover and address a client's needs. Because the HHA will be with the client more than anyone else, it is very important for him to report his observations to the supervisor.

## Developmental Disabilities

**Developmental disabilities** are disabilities that are present at birth or emerge during childhood, up to age 22. A developmental disability is a chronic condition that restricts physical and/or mental ability. These disabilities prevent a child from developing at a normal rate. Language, mobility, learning, and the ability to perform self-care may be affected. These disabilities include intellectual disabilities, Down syndrome, cerebral palsy, spina bifida, and autism spectrum disorder.

Often, an HHA's role is to help these clients by giving family caregivers a break. Home health aides help teach clients self-care and assist with activities of daily living. They also provide a role model for families in dealing with the disability. A brief description of some developmental disabilities follows:

**Intellectual disability:** Intellectual disability (formerly called *mental retardation*) is the most common developmental disability. An intellectual disability is neither a disease nor a mental health disorder. People with an intellectual disability develop at a below-average rate. They have below-average mental functioning. They experience difficulty in learning, communicating, and moving, and may have problems adjusting socially. The ability to care for themselves may be affected. The potential for living independently and for achieving financial independence may be limited.

There are four different degrees of this disability: mild, moderate, severe, and profound. The level of care required for individuals with an intellectual disability can range from relatively independent living with mild intellectual disability to a need for skilled, 24-hour care for a person who has profound intellectual disability.

Clients who have an intellectual disability have the same emotional and physical needs that others have (Fig. 17-6). They experience the same

emotions, such as anger, sadness, love, and joy, as others do, but their ability to express their emotions may be limited.



**Fig. 17-6.** People who have an intellectual disability have the same emotional and physical needs that others do.

For clients who have an intellectual disability, the main goal of care is to help the person have as normal a life as possible. This means an HHA should recognize the client's individuality, basic human rights, and physical and emotional needs, as well as any additional needs.

Some clients and/or their families will use the term *intellectually disabled*, while others may use *developmentally delayed*. Home health aides should respect each client's wishes about how to refer to this disability.

Parents may have strong reactions when they learn that their child has an intellectual disability. They may be depressed or feel shock, anger, guilt, or grief. They may deny that there is anything wrong. They may even feel ashamed of the child and neglect her. Any signs of adjustment difficulties should be reported to the supervisor. He may be able to recommend counseling or support groups.

### Guidelines: Intellectual Disability

- G** Treat adult clients as adults, regardless of their intellectual abilities.
- G** Praise and encourage often, especially positive behavior.



- G** Help teach clients to perform ADLs by dividing a task into smaller units.
- G** Promote independence, but also assist clients with activities and motor functions that are difficult.
- G** Encourage social interaction.
- G** Repeat what you say to make sure clients understand.
- G** Be patient.

**Down Syndrome:** Down syndrome, also called Trisomy 21, is most often caused by an abnormal cell division, resulting in an extra number 21 chromosome (three copies of chromosome 21, instead of the usual two copies). People who are born with Down syndrome experience different degrees of intellectual disability, along with physical symptoms. A person with Down syndrome typically has a small skull, a flattened nose, short fingers, and a wider space between the first two fingers and the first two toes. As with some types of intellectual disabilities, a person with Down syndrome can become fairly independent.

#### Guidelines: Down Syndrome

- G** Give the same type of care and instruction that you would for any other person with an intellectual disability.
- G** Praise and encourage often, especially positive behavior.
- G** Help teach the client to perform ADLs by dividing a task into smaller units.

**Cerebral Palsy:** People who have cerebral palsy had brain damage either while in the uterus or during birth. They may have both physical and mental disabilities. Damage to the brain stops the development of the child or causes disorganized or abnormal development. Muscle coordination and nerves are affected. People with cerebral palsy may lack control of the head, have difficulty using the arms and hands, and have

poor balance or posture. They may be either stiff or limp, and may have impaired speech. Gait and mobility may be affected. Intelligence may also be affected. With or without assistance, a person with cerebral palsy may be able to live independently.

#### Guidelines: Cerebral Palsy

- G** Allow the client to move slowly. People with cerebral palsy take longer to adjust their body position and may repeat movements several times.
- G** Maintain the client's body in as normal an alignment as possible.
- G** Talk to the client, even if she cannot speak. Be patient and listen.
- G** Use touch as a form of communication.
- G** Avoid activities that are tiring or frustrating.
- G** Be gentle when handling parts of the body that may be painful (Fig. 17-7).
- G** Promote independence and encourage socializing with friends and family.



**Fig. 17-7.** Be gentle when moving body parts of a client who has cerebral palsy.

**Spina Bifida** (*spy-na BIF-e-da*): Spina bifida literally means “split spine.” When part of the backbone is not well developed at birth, the spinal cord may bulge out of the person's back. Spina bifida can cause a range of disabilities. Some babies born with spina bifida will be able to walk and will experience no lasting disabilities.

Others may be in a wheelchair and/or may have little or no bladder or bowel control. In some cases, complications of spina bifida may cause brain damage.

Guidelines: Spina Bifida

- G If the client is an adult, provide assistance with range of motion exercises and ADLs. Help perform light housecleaning duties.
- G If an infant or child has spina bifida, perform tasks that help the parents manage and stabilize the home.
- G Be a positive role model for the family and the client in learning to deal with the client's disabilities.

**Autism Spectrum Disorder (ASD):** Autism spectrum disorder is a developmental disability that affects social skills and communication. It appears in early childhood, usually by age 3. Parents may notice that a child does not engage in pretend play or has problems with communication and social interaction. A diagnosis may be made after comprehensive testing, including physical and neurological examinations, among other screening tests.

Social skills and communication issues include being unable to communicate using words, being withdrawn, and being unable to make eye contact. Intense tantrums, repetitive body movements, aggression, a short attention span, and an inability to be empathetic are also symptoms of autism spectrum disorder. Intensely focused interests (for example, learning everything about airplanes) are common.

The exact cause of autism spectrum disorder is unknown, but genetics may be a factor. Boys are more likely to have ASD.

Treatment includes many types of therapies, including behavioral, speech, and occupational therapies, along with social skills training. Nutrition management can also be beneficial.

Having familiar caregivers and keeping a routine may be helpful. Ideally, treatment should be started early and must be tailored to the individual.

Community Resources for Developmental Disabilities

- There are many services available to help people who have developmental disabilities. Home- and community-based waivers may be available. These pay for certain services for people who are chronically ill or disabled. Each state's department of health should have more information. Some additional resources include the following:
- American Association on Intellectual and Developmental Disabilities (aaidd.org, 202-387-1968)
  - Autism Science Foundation (autismsciencefoundation.org, 914-810-9100)
  - National Down Syndrome Congress (ndsccenter.org, 800-232-6372)
  - Special Olympics (specialolympics.org, 800-700-8585)
  - Spina Bifida Association (spinabifidaassociation.org, 800-621-3141)
  - United Cerebral Palsy (ucp.org, 800-872-5827)

Physical Disabilities

Physical disabilities that are not developmentally related are the result of diseases or accidents. These clients must adjust physically, as well as mentally, to a gradual or sudden loss of ability. Chapter 9 contains more information on diseases that cause physical disabilities.

10. List important changes to report and document for a client with disabilities

Again, each client is an individual and will have different abilities. As with any client, the home health aide should report changes to the supervisor and document them. For example, if a client with some vision impairment is suddenly unable to see anything, the HHA should report this immediately.



Being very careful to observe and report changes in the skin is vital. This is particularly true for clients with disabilities that affect mobility. Pressure injury prevention is an important role of the home health aide.

Emotional changes should also be observed and reported. Clients may be at risk for depression. Any signs of depression, including moodiness, weight loss or gain, fatigue, or withdrawal should be reported.

## Chapter Review

1. List four factors that affect how well a person copes with a disability.
2. List ten diseases and disorders that may cause disability.
3. Name seven activities that may pose challenges for a person with a disability.
4. Why is it important for an HHA to be aware of and sensitive to her clients' preferred terms for referring to their disabilities?
5. Why should an HHA not take over a task for a client who has a disability even if she knows she can do it better and faster?
6. What are three things that an HHA can do for a client who has a disability with regard to sexuality and intimacy?
7. List six basic skills that apply to working with clients with disabilities.
8. Describe one thing an HHA can do to promote each of the five goals outlined in Learning Objective 7.
9. Choose one of the five qualities of excellent service described in Learning Objective 8 and explain why it would be important to a client with a disability.
10. What are developmental disabilities?

**Matching.** For each of the following terms, write the letter of the correct definition from the list below.

11. \_\_\_\_ Autism Spectrum Disorder
  12. \_\_\_\_ Cerebral Palsy
  13. \_\_\_\_ Down Syndrome
  14. \_\_\_\_ Intellectual Disability
  15. \_\_\_\_ Spina Bifida
- (A) A disability that results from suffering brain damage in the uterus or during birth; muscle coordination and nerves are affected.
- (B) A disability that occurs when the backbone is not well developed at birth, and the spinal cord may bulge out of the person's back; it may cause brain damage.
- (C) A condition that causes below-average intellectual abilities in varying degrees; children may be slow to develop.
- (D) People with this disability experience different degrees of intellectual disability. They typically have a small skull, flattened nose, and short fingers.
- (E) A developmental disability that affects social skills and communication; repetitive body movements and an inability to be empathetic are symptoms.
16. Why is it important for an HHA to observe a client's skin changes?
17. Why should an HHA report a client's emotional changes?