

PRINCIPLES OF CAREGIVING DEVELOPMENTAL DISABILITIES MODULE

CHAPTER 1: KNOWLEDGE OF DEVELOPMENTAL DISABILITIES

CONTENT:

- A. Developmental Disabilities
- B. Introduction to Human Development
- C. The Four Developmental Disabilities
- D. Responding to Seizure Activity
- E. Sensory Integration Challenges
- F. General Guidelines for Working with People with Disabilities

COMPETENCIES:

(TO KNOW OR BE ABLE TO:)

1. What a developmental disability means.
2. Four conditions to qualify for the Division of Developmental Disabilities.
3. Recognize affects of Autism.
4. Recognize affects of Cerebral Palsy.
5. Recognize affects of Cognitive Disability.
6. Recognize affects of Epilepsy.
7. Factors that contribute to seizure activity.
8. Recognize when a person is having seizure activity.
9. What to do when a person is having seizure activity.
10. What not to do when someone is having a seizure.
11. When to call 911 when a person is having a seizure.
12. Document and report seizure activity.
13. Ways to support a person after seizure activity.
14. How sensory integration challenges may affect a person.

KEY TERMS:

Autism

Epilepsy

Cerebral Palsy

Seizure Activity

Cognitive Disability

Sensory Integration Challenges

Developmental Disability

A. DEVELOPMENTAL DISABILITIES

Developmental disability is a broad term used to describe delays in one or more developmental category, and therefore may have no specific cause or cure. There are many causes of developmental delay. These can include early brain or birth injuries, genetic disorders and environmental factors. Environmental factors include poor maternal nutrition, exposure to toxins, or infections passed from a mother to her baby during pregnancy.

Exercise: Which disabilities do you know?

For example: Down syndrome, blindness

Discussion: What is the difference between a developmental disability and other disabilities?

Developmental disabilities (DD) are severe, chronic disabilities attributable to mental and/or physical impairment, which manifest before age 18 and are likely to continue indefinitely. They result in substantial limitations in these areas:

- Self – care.
- Receptive and expressive language.
- Learning.
- Mobility.
- Self-direction.
- Capacity for independent living.
- Economic self-sufficiency.

Note: In order to receive services in Arizona, the Division of Developmental Disabilities recognizes four qualifying diagnoses for individuals age 6 and above:

1. Autism.
2. Cerebral Palsy.
3. Cognitive disability.
4. Epilepsy.

Who do we support?

Individuals with disabilities are infants, children, adolescents, young adults and older adults who have a life to live in the same respect as everyone else. Public concern and attention is directed toward providing the opportunities for life, liberty and the pursuit of happiness to all citizens. Direct Care Workers (DCWs) will be joining a large and distinguished group of parents, teachers, physicians, therapists, professionals and friends who are working to support individuals with disabilities as they lead their lives.

B. INTRODUCTION TO HUMAN DEVELOPMENT

It is important for Direct Care Workers to remember that no two individuals (with or without a disability) are alike. People with the same disability will learn and grow differently. Also, there are different types of development.

Social	Physical
Speech / language	Cognitive
Self-help	Emotional

_____ **development** is the gradual gaining of control of large and small muscles. It includes the development of large muscle skills such as sitting, crawling, walking, running, and throwing; and small muscle skills such as holding, pinching, and flexing fingers and toes.

_____ **development** is the process of learning to think and to reason.

_____ **development** is the development of daily living skills such as using the bathroom, self feeding, dressing and so forth.

_____ **development** is the process of learning to communicate with others through verbal or other communication means.

_____ **development** is the process of getting to know and value the other people. It involves being able to establish and maintain relationships, develop social skills, and gets along with others. It includes learning to share, cooperate, take turns, and negotiate with others.

_____ **development** refers to the feelings people have about themselves, other people in their lives and the environment in which they live. This includes their relationships with others and their emotional reactions to people and things in their environment.

C. THE FOUR DEVELOPMENTAL DISABILITIES

1. Autism

... affects social and communication abilities.

Autism is a condition characterized by severe disorders in communication and behavior resulting in limited ability to communicate, understand, learn and participate in social relationships. Some people may be mildly affected while others may be more significantly affected and require around the clock supports.

Characteristics of autism

Social interaction

The most obvious symptom of autism is impaired social interaction. Individuals with autism:

- May fail to respond to their names.
- Often avoid looking at other people.
- Have difficulty interpreting tone of voice or facial expressions.
- May not respond to others' emotions.
- Watch other people's faces for cues about appropriate behavior.
- Appear to be unaware of others' feelings toward them and of the negative impact of their behavior on other people.
- May be unaware of personal space.

Communication

Problems with verbal and nonverbal communication may include:

- Repetitive speech, noises and phrases, unusual rate, pitch or rhythm of speech.
- Speech or vocalizations may be more for sensory stimulation than communication.
- Trouble with initiating or sustaining conversation.
- Individuals may never develop spoken language. (But they do communicate!)

Limited or unusual activities and interests

People with autism may:

- Engage in repetitive movements (spinning, rocking, hand slapping).
- Be obsessive about routines.
- Require their physical environment to be set up in a specific way.
- Have intense and obsessive interests around specific subjects or objects (birthdates, time zones, spinning wheels, strings, etc.).

Unusual response to sensory stimuli (things experienced through the senses; sounds, textures, pressures, smells, sights, lights, etc.)

Unusual sensitivities may contribute to behavioral symptoms such as resistance to being touched and may also contribute to:

- Abnormal responses to light, sounds, touch, or other sensory stimulation.
- Repetitive movements such as rocking and hair twirling, or in self-injurious behavior (e.g. biting or head-banging).
- Reduced sensitivity to pain.

In addition to the characteristics listed above, people with autism may have special dietary needs that will require reviewing the person’s plan and getting to know the individual.

2. Cerebral Palsy

... affects the brain’s ability to communicate effectively with the muscles.

Cerebral Palsy results from a brain injury that may occur before or at the time of birth, or up until the age of six. “Cerebral” refers to the brain and “palsy” refers to muscle weakness or poor control. Injury to the brain affects the messages the brain sends to the muscles. The muscles affected may be just a part of the body, and sometimes it affects the entire body. Although permanent, the brain abnormality does not get worse over time. Uncontrolled movements and muscle tightness (spasticity) may occur with varying severity.

Cerebral Palsy is not progressive; however secondary conditions such as muscle control may get better or worse over time, or stay the same.

Note: Although communication may be difficult, a person with cerebral palsy may not have any intellectual challenges

Depending on the areas of the brain affected, one or more of the following may occur:

- Muscle tightness.
- Involuntary movement.
- Gait or mobility problems.
- Difficulty swallowing and feeding.
- Difficulty with vision, hearing, or articulation of speech.
- Problems with breathing due to postural difficulties.
- Skin disorders due to pressure sores.

3. Cognitive disability

... affects how a person learns

Cognitive disability, also referred to as intellectual disability, is characterized by challenges in learning which causes limitations in areas of daily life. These limitations can cause problems in school, work, and leisure activities, social and communication skills, and activities of daily living. People with a cognitive disability can and do learn new skills but may need additional support or adapted teaching strategies.

In Arizona a person needs to have an IQ score below 70 to qualify for services through the Division of Developmental Disabilities.

4. Epilepsy (seizures)

... affects electrical / chemical impulses in the brain

Epilepsy is a long-term condition that causes repeated seizures if it is not treated (and sometimes despite treatment). There are many kinds of seizures, but all involve abnormal electrical activity in the brain that causes an involuntary change in body movement or function, sensation, awareness, or behavior.

A seizure is a sudden surge of electrical activity in the brain that usually affects how a person feels or acts for a short time. Seizures are not a disease in themselves. Instead, they are a symptom of many different disorders that can affect the brain. Some seizures can hardly be noticed. Others may involve the entire body and affect a person in many aspects of their life.

Seizures may be related to a brain injury or a family tendency, but often the cause is completely unknown. The word "epilepsy" does not indicate anything about the cause of the person's seizures or how severe they are. Epilepsy affects people in varying degrees. In most cases, they can be controlled by treatment such as medication, surgery, or nerve stimulation. For some people, treatment does not adequately control the seizures.

D. RESPONDING TO SEIZURE ACTIVITY

Recognizing a Seizure

How a seizure affects a person, and what it may look like, depends on the part of the brain that is involved in the seizure. A seizure is caused by an electrical disturbance in the brain. Seizures can vary in how they look depending on the individual.

Responding to Seizures

If a person you are supporting is experiencing a seizure, respond the way that you have been trained in your individual orientation to that person and your First Aid training. **ALWAYS FOLLOW THE INDIVIDUAL PERSON'S SEIZURE PROTOCOL.**

Each person served by DDD has an Individual Support Plan that includes a listing of "risks" that may affect the person. A person with seizures should have a risk assessment that outlines specific steps to follow when this person has a seizure.

For convulsive type seizures:

(convulsive means there is uncontrollable movement of the muscles)

- Stay calm and time the seizure.
- If the person is having a convulsive type seizure, loosen any tight clothing and remove eyeglasses if they wear them.
- Clear the area of any potential hazards that could cause an injury to the individual such as hard, sharp, or hot objects, but do not interfere with their movements.
- If you can do so safely, turn the person's body to the side to permit the draining of fluids.
- Place something soft under the head.
- Stay with the person. Continue to monitor the person after the seizure.
- If the person is tired, assist him/her to a quiet comfortable place and allow time to rest.

For non-convulsive type seizures (seizures that may involve the person's senses or behavior, but that do not involve convulsions.)

- Time the seizure.
- Be available if they need assistance.

What not to do during a seizure

- Do NOT attempt to stop the seizure!
- Do NOT restrain the person or try to hold them down in any way!
- Do NOT force anything between their teeth or put anything in their mouth!
- Do NOT give the person anything to eat or drink until s/he has fully recovered consciousness!

When to call 911

- **Follow the person's seizure protocol.**
- If the person does not have a known seizure disorder, call 911.
- If the seizure or recovery is different than what is typical for that person, call 911.
- If a seizure lasts longer than 5 minutes, call 911 (unless you have been instructed otherwise in the individual orientation to the person).
- If a person is having repeated seizures, call 911.
- If the person's well being is in question, call 911.
- If a person has trouble breathing after the seizure (lips or nail beds turning blue), call 911.
- If a person is injured or seems to be in pain, call 911.
- If you think the person's health, well-being, or life is in danger, call 911.

Repeated Seizures can be life-threatening!
CALL 911!

Almost all seizures end naturally with no intervention within a few minutes. The person may be tired and confused following a seizure and need to sleep. If however a person does not completely recover from one seizure before beginning another one, it's possible that they are experiencing *status epilepticus*, a life-threatening seizure. If in question, call 911!

Supporting a person after a seizure

- Provide any needed first aid for minor injuries or call 911 if necessary.
- Be calm, friendly and reassuring.
- Help the person to an area where they can rest comfortably.
- The person is likely to be very tired. Allow them to rest. They may sleep very deeply for a period of time following a seizure.
- The person may seem confused or disoriented following a seizure.

After a seizure

Once the seizure is over, and the person is safe and comfortable, you will need to document some information about the seizure. When completing your documentation of the seizure:

- Note the time the seizure started and ended.
- Note the characteristics of the seizure.
 - Did the person lose consciousness?
 - Were they incontinent?
 - Did they experience convulsions?
 - What body parts were involved?
 - Was there a change in the coloring of the skin, or a blue tint to the lips or nail-beds?
 - What was the individual's condition following the seizure, i.e. were they confused, did they have a headache, were they aware of their environment?
- When it is safe to do so, write a seizure report and/or incident report following your agency's policy.
- After a seizure, a person is often very tired. Assist them as necessary to a place where they can rest.

Factors that may contribute to a seizure

There are many factors that may increase the likelihood that a person with epilepsy will experience a seizure. The triggers that may affect a person will depend on their particular type of epilepsy, and many other factors. Some things to consider include:

- Changes in medication or missing a dosage of a seizure medication.
- Lack of sleep / exhaustion.
- Stress.
- Alcohol or drug use (including prescription medications, recreational drugs and over-the-counter medications).
- Hormonal changes.
- Exposure to toxins.
- Nutritional changes or deficiencies.
- Becoming overheated or dehydrated.

E. SENSORY INTEGRATION CHALLENGES

Many people with developmental disabilities also experience sensory integration challenges. Individuals process sensation from the environment or from their bodies (e.g. what they feel or hear) in an inaccurate way.

A professional therapist may develop a specific program to address sensory problems that include activities for a direct care worker to follow.

Signs of sensory integration challenges MAY include:

- Problems with movement such as difficulty walking on uneven surfaces.
- Poor spatial awareness (awareness of things in the space around us).
- Being overly sensitive to touch, movements, sights, or sounds.
- Sensitivity to types of fabric used in clothing, etc.

F. GENERAL GUIDELINES FOR WORKING WITH PEOPLE WITH DEVELOPMENTAL DISABILITIES

Get to know the person you support. Just like anyone else, the people who are most supportive to us are those who know us best. We want to take the time to develop that knowledge.

Provide clear verbal instructions. It is best to provide clear simple verbal instructions. Use the name of the person to get his/her attention and then present the instruction or direction.

Provide opportunities for growth. Do not assume that because someone has a disability they cannot do things for themselves. Encourage the person to try new things and to do tasks with as little assistance as possible.

Model correct behavior. The person will learn from watching you. Use proper behaviors so the individual can follow. Sometimes a task or behavior must be repeated many times until the person learns it. Be patient and positive.

Many people will need assistance in learning and in other areas. They may be getting physical, occupational and speech therapy services. Always speak clearly and follow through with any activities provided by the therapist. Supporting therapy goals through informal or formal practice of goals is essential.

Use a consistent approach. Consistency provides a sense of security.

Be aware of how the environment affects the person you are supporting. Some people tend to be sensitive to sound, light, touch and/or other factors.

Plan for transitions. Changes can be difficult, by giving cues about the change ahead of time the transition from one activity to another will go smoother. Transitions are difficult for many people.