

Facilitator Manual



DEVELOPMENTAL DISABILITIES

A training program
for caregivers, personal
attendants and direct
support professionals.

THE ARIZONA DIRECT CARE CURRICULUM PROJECT.

This material was created for educational purposes by the Arizona Direct Care Curriculum Project. It is intended as reference material for persons seeking to learn more about this topic. Neither the Department of Economic Security, its Division of Aging and Adult Services, nor any individuals or organizations associated with this project, guarantee that this information is the definitive guide on this topic, nor does it guarantee that mastery of this material assures that learners will pass any required examination.

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For more information about the curriculum project, please visit the Arizona Direct Care Initiative website at www.azdirectcare.org.

PREFACE TO THE PRINCIPLES OF CAREGIVING

The Development of Standardized Direct Care Professional Training in Arizona

The need for home and community-based caregiving is one of the most compelling issues of our time. It will affect nearly every family in America. In order to be ready to meet the increasing demand for home and community-based services, Arizona must develop a capable and compassionate workforce of caregivers. We are better prepared to meet these challenges through the *Principles of Caregiving* training for caregivers, personal attendants, and direct support professionals.

In 2004, Governor Janet Napolitano appointed the Citizens Work Group on the Long Term Care Workforce (CWG) to further develop and provide recommendations for improving the quality of the long-term care workforce. In 2005, the CWG laid out ten recommendations. One called for the implementation of a standardized, uniform, and universal training curriculum for the direct care workforce.

The Direct Care Curriculum Project is a partnership between the Arizona Department of Economic Security, the Arizona Health Care Cost Containment System, the Developmental Disabilities Planning Council (formerly the Governor's Council on Developmental Disabilities), the Arizona Department of Health Services, and the Direct Care Workforce Committee. The *Principles of Caregiving* training manuals were created to help establish a high-quality training program for direct care and direct support professionals in Arizona. Many individuals and agencies were involved, representing home care providers, community colleges, advocacy organizations, and state agencies. Refer to the Appendix for a list of acknowledgments.

NOTES TO THE STUDENTS

Principles of Caregiving: Developmental Disabilities is a Level 2 module of the *Principles of Caregiving* series. It builds on the Fundamentals module, and contains advanced material for DCWs working with individuals with developmental disabilities. The Fundamentals module should be completed first. Some review may be necessary before completing this module.

This module is independent of the other Level 2 modules in the series. You can complete this portion of the training without studying the other modules.

Depending on the needs of your employer and the clients served, you may not need all the knowledge and skills presented in Developmental Disabilities, but you are encouraged to study the whole program. The *Principles of Caregiving* curriculum is designed to provide a well-rounded introduction to caregiving and direct supports, and you will be prepared to work for a variety of clients and employers.

Principles of Caregiving includes the following modules:

- Level 1: Fundamentals
- Level 2: Aging and Physical Disabilities
- Level 2: Developmental Disabilities
- Level 2: Alzheimer's Disease and Other Dementias

Competencies for Arizona Direct Care Workers

The competencies are the basis for the training and testing of any staff providing housekeeping or homemaker services, personal care, or attendant care services for a state-funded program in Arizona. The *Principles of Caregiving* books address all of the competencies and help you prepare for the Arizona DCW tests. For a list of competencies, see the Appendix of this module, or refer to the Arizona Direct Care Initiative website at www.azdirectcare.org, click on Competencies.

Learning Objectives

Each chapter of the Developmental Disabilities module begins with an introductory page that lists the learning objectives and the key terms for that particular chapter. Some sections also list skills; these are procedures that you should practice and demonstrate to your instructor. The following symbol is usually used to identify skills:

N Procedures that you need to practice and demonstrate.

PRINCIPLES OF CAREGIVING: DEVELOPMENTAL DISABILITIES

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PRINCIPLES OF CAREGIVING DEVELOPMENTAL DISABILITIES MODULE

CHAPTER 1: KNOWLEDGE OF DEVELOPMENTAL DISABILITIES

FACILITATOR GUIDE

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

Estimated time for this chapter: 1 hour

Needed Materials:

1. Facilitator Guide
2. Participant Guides

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

Facilitator Note:

Review the following information with the larger group. You may want to read sections aloud, ask for volunteers to read it, or allow adequate time for the group to read it on their own.

A. DEVELOPMENTAL DISABILITIES

Facilitator Note:

Introduce this section by discussing how the knowledge of areas of development helps us to recognize the areas of development affected when a person has a developmental disability. The person's Individual Support Plan (ISP) summarizes strengths and support resources needed in each area of development.

In order to qualify for services through the Department of Economic Security, Division of Developmental Disabilities, a person must be diagnosed as having a developmental disability that meets certain criteria (as outlined in ARS 36-551).

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

Facilitator Note: Discuss the following topics related to human development.

The stages of development will follow patterns that are based on basic principles typical of all people, whether they have disabilities or not. These principles state that development is:

- Similar in all people. While every person is unique, development occurs in sequences that are predictable.
- An orderly process with stages (patterns) that can be predicted. Knowing the predictable sequences of behavior helps in recognizing typical (normal), patterns of behavioral change and growth and enables parents, educators, and other professionals to develop individualized programs.
- Proceeds at different rates from the general to the specific, from the upper portions of the body toward the lower portions –from head to toe, and from the center of the body to the outer body parts.

Facilitator Note:

A developmental domain or area of development is a category of skill and growth in a particular area. Individuals don't develop in just one area in isolation. The skills in each domain or area affect the others, and a delay in one area can negatively affect development in other domains. For example, if a person is experiencing challenges in the area of emotional development, this could result in behavior that affects his/her ability to be in a classroom setting. Although the challenge is in the area of emotional development, the person's behavior may interfere with his/her attention to learning and affect cognitive 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

Physical 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.

Cognitive development is the process of learning to think and to reason.

Self-help development is the development of daily living skills such as using the bathroom, self feeding, dressing and so forth.

Speech/Language development is the process of learning to communicate with others through verbal or other communication means.

Social 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.

Emotional 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

Facilitator Note:
Stress that this is general information about autism and that each individual is unique. They

may or may not see some or all of these characteristics depending on the individual.

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

Facilitator Note:

There are many misconceptions and fears about supporting a person who experiences seizures. Be sure to ask the group to share their knowledge and experiences in this area. This will give you the opportunity to address any misconceptions that the participants may have. Allow plenty of time for the participants to ask questions. Incorporate a current video about epilepsy or other visual training tools in this section if possible.

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.**

Facilitator Note:

Emphasize this point! Be sure that the participants know where to find a copy of the plan, or who to ask for it.

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.

Facilitator Note:

Psychomotor or Temporal Lobe Seizures are an example of a non-convulsive seizure. During these types of seizures a person may smell strange odors that aren’t actually present, have unexplained feelings, or have a sudden taste in their mouth.

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.

Facilitator note:

Sensory integration is the neurological process of organizing information from one's body and from the outside world for use in daily life. Sensory integration is an important foundation for more

complex learning and behavior. For most people, sensory integration develops in the course of typical development as the ability to adapt to incoming sensations. When sensory integration does not proceed fully, a number of problems in learning, development, or behavior may emerge. These challenges may affect a person's self-esteem, self control and attention span.

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.

Facilitator Note:

If a person shows signs and symptoms of having a sensory integration challenges, an assessment can be completed by a qualified occupational therapist. Based on the assessment, the therapist will make recommendations for appropriate therapy and treatment. The therapist will provide specific directions on the implementation of specific therapeutic interventions that can be used by the person on a day-to-day basis.

Source: www.sensory-processing-disorder.com

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.

Instructor Resource Materials

MEDICATIONS COMMONLY USED TO TREAT EPILEPSY - INSTRUCTOR RESOURCE MATERIALS

Facilitator Note:

This list is NOT inclusive. New medications are being developed / used all the time.

Tegretol or Carbatrol (carbamazepine)

First choice for partial, generalized tonic-clonic and mixed seizures.

Common adverse effects include fatigue, vision changes, nausea, dizziness, and rash.

Zarontin (ethosuximide)

Used to treat absence seizures.

Adverse effects include nausea, vomiting, decreased appetite, and weight loss.

Felbatol

Treats partial and some generalized seizures.

Side effects include decreased appetite, weight loss, inability to sleep, headache, and depression. The drug can rarely cause bone marrow or liver failure. Therefore the use of the drug is limited and patients taking it must have blood cell counts and liver tests regularly during therapy.

Gabitril

Used with other epilepsy drugs to treat partial and some generalized seizures.

Common side effects include dizziness, fatigue, weakness, irritability, anxiety, and confusion.

Keppra

Used with other epilepsy drugs to treat partial seizures.

Side effects include tiredness, weakness, and behavioral changes.

Lamictal

Treats partial and some generalized seizures.

Has few side effects, but occasionally people report dizziness, insomnia, or rash.

Lyrica

Used to treat partial seizures.

Side effects include dizziness, sleepiness (somnolence), dry mouth, peripheral edema, blurred vision, weight gain, and difficulty with concentration/attention.

Neurontin (Gabapentin)

Used with other epilepsy drugs to treat partial and some generalized seizures.

Few lasting side effects. During the first weeks of treatment the person may experience tiredness and dizziness.

Dilantin (Phenytoin)

Controls partial seizures and generalized tonic-clonic seizures. Also can be given by vein (intravenously) in the hospital to rapidly control active seizures.

Side effects include dizziness, fatigue, slurred speech, acne, rash, and increased hair (hirsutism). Over the long term the drug can cause bone thinning.

Topamax

Used with other drugs to treat partial or generalized tonic-clonic seizures.

Side effects include sleepiness, dizziness, speech problems, nervousness, memory problems, visions problems, weight loss.

Trileptal

Treats partial seizures.

Most common side effects are tiredness, dizziness, headache, blurred vision, or double vision.

Depakene, Depakote (valproate, valproic acid)

Used to treat partial, absence, and generalized tonic-clonic seizures.

Common side effects include dizziness, nausea, vomiting, tremor, hair loss, weight gain, depression in adults, irritability in children, reduced attention, and a decrease in thinking speed. Over the long term, the drug can cause bone thinning, swelling of the ankles, irregular menstrual periods. More rare and dangerous effects include hearing loss, liver damage, decreased platelets (clotting cells), and pancreas problems.

Zonegran

Used with other drugs to treat partial seizures.

Adverse effects include drowsiness, dizziness, unsteady gait, kidney stones, abdominal discomfort, headache, and rash.

Valium and similar tranquilizers such as Klonopin or Tranxene

Effective in short-term treatment of all seizures. Used often in the emergency room to stop a seizure.

Tolerance develops in most within a few weeks, so the same dose has less effect over time.

Side effects include tiredness, unsteady walking, nausea, depression, and loss of appetite. In children they can cause drooling and hyperactivity.

Source: "Epilepsy Health Center". WebMD. 6/1/10
<<http://www.webmd.com/epilepsy/medications-treat-seizures>>.

OTHER TREATMENTS FOR EPILEPSY - INSTRUCTOR RESOURCE MATERIALS

Surgery

There are two types of surgery commonly used to treat epilepsy.

- **Resection** – In a resection, the surgeon removes the part of the brain that is causing the seizure.
- **Disconnection** – In disconnection the surgeon interrupts the nerve pathways that allow for the spread of the seizure across the brain.

Source: "Types of Surgery". Epilepsy.com. 5/15/10
<http://www.epilepsy.com/EPILEPSY/types_surgery>.

Vagus Nerve Stimulation

Vagus nerve stimulation (VNS) is designed to prevent seizures by sending regular, mild pulses of electrical energy to the brain via the vagus nerve. These pulses are supplied by a device something like a pacemaker.

The VNS device is sometimes referred to as a "pacemaker for the brain." It is placed under the skin on the chest wall and a wire runs from it to the vagus nerve in the neck.

The VNS will send an automatic pulse to the brain at regularly scheduled intervals. Additional pulses can be activated if necessary by passing a magnet across the area of the body where the VNS has been implanted.

Source: "Vagus Nerve Stimulation". Epilepsy.com. 5/15/10 <
<http://www.epilepsy.com/EPILEPSY/vns>>.

FETAL ALCOHOL SYNDROME – INSTRUCTOR RESOURCE MATERIALS

Fetal Alcohol Syndrome (FAS)

FAS is a lifelong, yet completely preventable set of physical, mental and neurobehavioral birth defects. FAS is the leading known preventable cause of cognitive disability and birth defects.

What is the cause?

Consumption of alcohol prior to conception by either the father or the mother, and or consumption by the mother during pregnancy.

What are the symptoms?

Some people with FAS have only a few of these traits, while others have many. Among the most common traits are:

Growth deficiencies: Small body size and weight, slower than normal development and failure to catch up.

Skeletal deformities: Deformed ribs and sternum; curved spine; hip dislocations; bent, fused, webbed, or missing fingers or toes; limited movement of joints; small head.

Facial abnormalities: Small eye openings; skin webbing between eyes and base of nose; drooping eyelids; nearsightedness; failure of eyes to move in same direction; short upturned nose; sunken nasal bridge; flat or absent groove between nose and upper lip; thin upper lip; opening in roof of mouth; small jaw; low-set or poorly formed ears.

Organ deformities: Heart defects; heart murmurs; genital malformations; kidney and urinary defects.

Central nervous system handicaps: Small brain; faulty arrangement of brain cells and connective tissue; cognitive disability -- usually mild to moderate but occasionally severe; learning disabilities; short attention span; irritability in infancy; hyperactivity in childhood; poor body, hand, and finger coordination.

DDD Eligibility Criteria for Children Birth to Age 6

In Arizona, a child under the age of six years may be eligible for services if there is a strongly demonstrated potential that the child has or will have a developmental disability as determined by appropriate tests.

Developmental delays begin in childhood and occur when children have not reached predictable developmental milestones by the expected time period. For example, if the normal range for learning to walk is between 9 and 15 months, and a 24-month-old child is still not walking, this could be considered a developmental delay.

Developmental delays can occur in all five or the areas of development listed below or may just happen in one or more of the areas. Because growth in each area of development is related to growth in other areas, a difficulty in one area is likely to influence development in other areas. For example, if a child has a delay in speech and language development, it may very likely affect the child's social and emotional development. Additionally, some children with developmental delay will have other associated problems, such as problems with vision or hearing, behavioral problems or seizures.

To be eligible, a child age 0-6 shall meet at least one of the following criteria:

- a. Have a diagnosis of cerebral palsy, epilepsy, autism or cognitive disability.
- b. There is a strong demonstrated potential that a child is or will have a developmental disability (i.e. the parent or primary caregiver has a developmental disability and there is likelihood that without early intervention services the child will have a developmental disability).
- c. Have demonstrated a significant developmental delay which indicates that the child has a 50% delay in one of the following five developmental domains or that the child has a 25% delay in two or more of the following five domains (0-3):
 1. Physical (fine and/gross motor, vision or hearing).
 2. Cognitive.
 3. Communication.
 4. Social Emotional.
 5. Self Help.

DDD Eligibility Criteria for People Age 6 and Above

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 numerous causes of developmental delay including early brain or birth injuries, genetic disorders and environmental factors including poor maternal nutrition, exposure to toxins or infections passed from a mother to her baby during pregnancy.

In Arizona, the Division of Developmental Disabilities recognizes four qualifying diagnoses for individuals age 6 and above:

1. Cognitive Disability (formerly Mental Retardation).
2. Epilepsy.
3. Autism.
4. Cerebral Palsy.

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 three or more of the following areas:

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

SELF-CARE:

Self Care means the performance of personal activities that sustain health and hygiene appropriate to age and culture. This includes bathing, using the bathroom, tooth brushing, dressing and grooming.

Examples include:

- Assistance to shower/bathe without assistance.
- Assistance to dress / undress without assistance.
- Assistance to prepare or eat meals without assistance.

RECEPTIVE AND EXPRESSIVE LANGUAGE: Receptive and expressive language means the process of understanding and participating in conversations in the person's primary language, and expressing needs and ideas that can be understood by others.

Examples include:

- Assistance to participate in a conversation without visual cues like communication boards, captioning or sign language.
- A person with receptive language challenges may require assistance to interpret or understand incoming messages or instructions.
- A person with expressive language challenges may require assistance, coaching or interpretation to express themselves.

LEARNING: Learning means the ability to acquire, retain and apply information and skills.

Examples include:

- Inability to read and write.
- Inability to retain new information.
- Inability to learn new information.

MOBILITY: Mobility means the skill necessary to move safely and efficiently from one location to another within the person's home, neighborhood and community.

Examples include:

- Assistance from others is regularly required to get around in the community.
- Modifications or the use of adaptive technology are required to get around.
- Range of travel is severely limited.

SELF-DIRECTION: Self-Direction means the ability to manage one's life.

Examples include:

- Inability to begin and carry through on tasks without intense supervision.
- Inability to monitor one's own behavior.
- Inability to make decisions or follow through on them.

CAPACITY FOR INDEPENDENT LIVING: Capacity for Independent Living means the performance of necessary daily activities in one's own home and community.

Examples include:

- Inability to identify medical / health needs.
- Inability to perform housekeeping tasks.
- Inability to access community resources (shopping, medical, entertainment etc.).

ECONOMIC SELF-SUFFICIENCY: Economic self-sufficiency means the ability to independently locate, perform and maintain a job that provides income above the federal poverty level.

Examples include:

- Inability to get a job.
- Inability to hold a job.
- Inability to perform work at a level that results in adequate compensation.

PRINCIPLES OF CAREGIVING DEVELOPMENTAL DISABILITIES MODULE

CHAPTER 2 - WORKING WITH PEOPLE WITH DEVELOPMENTAL DISABILITIES

FACILITATOR GUIDE

CONTENT

- A. Person-Centered Approach
- B. Department of Economic Security-Division of Developmental Disabilities Mission, Vision and Values
- C. Individual Rights
- D. Self-Determination
- E. Person First Language
- F. Positive Relationships
- G. Professional Relationships

Estimated time for this chapter: 2.5 hours

Materials Needed:

1. Facilitator Guide
2. Participant Guides
3. Creative medium (newsprint paper, markers, molding clay, etc.)

**COMPETENCIES:
(TO KNOW OR BE ABLE TO:)**

1. Important rights for people with developmental disabilities.
2. Give examples of Person-First Language.
3. Ways to build a positive relationship.
4. What self determination means.
5. Give examples of self determination.
6. Ways to maintain a professional relationship with the person you work for.

KEY TERMS:

Division of Developmental Disabilities	Ethical Behavior	Mission, Vision, Values
Person-Centered Approach	Person 1 st Language	Positive Relationships
Professional Relationships	Rights	Self-Determination

A. PERSON-CENTERED APPROACH

Note: Review the section on Philosophy in chapter 1 of the Fundamentals before doing the following exercises.

Exercise 1: List basic concepts and values of a person-centered approach.

1. *Give people choices (about foods, activities, when they want to bathe, etc.)*
2. *Let ...*
3. *Ask ...*

Exercise 2: Why are choice and self-determination important?

1. *Sometimes people feel useless if others do everything for them*
2. *Some people ...*
3. *...*

B. DES – DIVISION OF DEVELOPMENTAL DISABILITIES (DDD) MISSION, VISION AND GOALS

Facilitator Note:

Provide a brief explanation of what the Department of Economic Security/Division of Developmental Disabilities (DES/DDD) is. Point out that chapter 3 will provide more information about DDD.

Be sure to emphasize that following a person-centered approach means that the individual directs his or her own life, and we assist them in getting to where they want to be in their life. It also means that along that journey we honor their particular culture and beliefs and their personal preferences.

The Division of Developmental Disabilities (DDD) is the state agency that provides funding, support and services to individuals who have epilepsy, autism, cerebral palsy or a cognitive disability and who meet additional eligibility criteria. You will learn more about DDD in the next chapter.

Mission:

To support the choices of individuals with disabilities and their families by promoting and providing, within communities, flexible, quality, consumer-driven services and supports.

Vision:

Individuals with developmental disabilities are valued members of their communities and are involved and participating based on their own choices.

Values:

- Healthy relationships with people.
- Individual and family priorities and choices.
- Equal access to quality services and supports for all individuals and families.
- Partnerships and ongoing communication with individuals, family members, advocates, providers and community members.
- Developmental approaches – changing conditions that affect people rather than changing people who are affected by conditions.
- Individual freedom from abuse, neglect and exploitation with a balance between the right to make choices and experience life and individual safety.
- A diverse workforce that is motivated, skilled and knowledgeable of and uses the most effective practices known.
- An environment rich in diversity in which each person is respected and has the opportunity to reach their optimal potential.

- Individual’s right to choose to participate in and contribute to all aspects of their home and community life.
- A system of services and supports which are:
 - Responsive
 - Timely and flexible responses to internal and external customers;
 - Strengths-based
 - Recognizing people’s strengths, promoting self-reliance, enhancing confidence and building on community assets;
 - Effective
 - Ongoing identification of effective methods and practices and incorporation of those practices into operations; and
 - Accountable
 - To our customers and to the taxpayers.

Thoughts about the person-centered approach

Facilitator Note:

Be sure that the participants include on this page basic information about the principles of a person-centered approach, including: respecting cultural differences, individuals directing their own lives, and honoring preferences.

A person-centered approach to support involves:

Use this space to illustrate the mission, vision and values of DDD

Facilitator Note:

In the participant guide this space can be used for a creative representation of the Mission, Vision and Values either as a finished product or a place to work on a draft. If the participants will be using newsprint paper, whiteboards or another creative medium, this page can also be used for general notes.

Facilitator Notes (for section C. below):

Review the following information regarding individual rights with the group. Ask for VOLUNTEERS to read aloud. (Note: To help support a safe training environment for everyone you may want to allow participants who are uncomfortable reading aloud to “pass.”)

Activity:

Brainstorm all of the rights that you (participants) have as a member of this society at this time in this place.

Facilitator will capture the brainstorming and fill the easel pad/board with what the class brainstorms. Some prompting can occur regarding constitutional rights, rights upon reaching adulthood, little rights exercised every day, etc.

Once pad/board is full, circle with a different color those rights that are explicitly protected by law. These will probably not be the majority, will only include those specifically mentioned in statute such as the bill of rights – to vote, free speech, legal representation, due process, bear arms, etc. or others protected explicitly by law such as privacy, education, non-discrimination, etc.

NOTE: Whoever teaches this section will need to have a good command and understanding of those rights that are explicitly protected by law and those rights that are implicit.

Explain that most of the rights that we enjoy are implicit, meaning that we have the rights and if someone violates them often there are criminal statutes to prosecute them, but these rights are not explicitly protected by law. In other words there is not a law that says “you have the right to....” It is important to make this distinction, because implicit rights are often the first ones violated. One way that implicit rights can become explicit is by including them in rule, policy and documenting them. That is why, in part, that we have the policy on individual rights and responsibility.

Note: If you believe that a review of “implicit” and “explicit” rights is not effective for your audience, then just have them brainstorm their rights to emphasize that our rights are the same as those of the people we serve and that we need to be more explicit about expressing them to offer additional protections to the people that we serve.

Source: Adapted from DES/DDD Individual Rights training developed by the Deb Stadle and the Positive Behavior Support Workgroup.

C. INDIVIDUAL RIGHTS

A person with a developmental disability has the same rights, benefits, and privileges guaranteed by the constitutions and laws of the United States and the State of Arizona.

Activity:

Brainstorm all of the rights that you (participants) have as a member of this society at this time in this place.

According to the Arizona Department of Economic Security, Division of Developmental Disabilities Policy 1500, the rights of an individual with a developmental disability receiving supports and services through the Division include, but are not limited to:

1. Right to an initial Individual Support Plan prior to receiving supports and services;
2. Right to participate in the initial Individual Support Plan, periodic reviews and whenever possible the opportunity to select among appropriate alternative supports and services;
3. Right (if accepted for supports and services) to participate in, share in decision making and receive a written Individual Support Plan based upon relevant results of the assessment.
4. Right to information regarding the supports and services available through a provider and about related charges, including any fees for supports and services not covered by a third-party payor;
5. Right to a periodic review of the Individual Support Plan;
6. Right to be given written notice of his/her rights;
7. Right to exercise his/her rights as citizens;
8. Right to live in the least restrictive setting;
9. Right to protection from physical, verbal, sexual or psychological abuse or punishment;
10. Right to equal employment opportunity;
11. Right to fair compensation for labor;
12. Right to own, rent or lease property;
13. Right to marry and have children;
14. Right to be free from involuntary sterilization;
15. Right to express human sexuality and receive appropriate training;
16. Right to consume alcoholic beverages if 21 years of age or older unless contraindicated by orders of his/her primary care physician;

17. Right to presumption of legal competency in guardianship proceedings;
18. Right to be free from unnecessary and excessive medication;
19. Right to be accorded privacy during treatment and care of personal needs;
20. Right to confidentiality of information and medical records;
21. Right of a school-age individual to receive publicly-supported educational services;
22. Right of a child to receive appropriate supports and services, subject to available appropriations, which do not require the relinquishment or restriction of parental rights or custody except as prescribed in Arizona Revised Statutes 8-533 which describes the grounds needed to justify the termination of the parent-child relationship;
23. Right to consent to or withhold consent from participation in a research project approved by the Division management team or any other research project; right to knowledge regarding the nature of the research, potential effects of a treatment procedure as part of a research project; right to confidentiality; and the right to withdraw from the research project at any time;
24. Right of an individual who believes his/her rights have been violated to petition the Superior Court for redress unless other remedies exist under federal or state laws.
25. Right to withdraw from programs, supports and services, unless the individual was assigned to the Department by the juvenile court or placed in a secure facility by the guardian and court;
26. Right to an administrative review, if in disagreement with a decision made by the Division (by filing a written request for such with the Division Office of Compliance and Review and the right to appeal the decision and;
27. Right to contact the Human Rights Committee.

When an individual with a developmental disability reaches his/her legal age (18 in Arizona except for drinking alcohol which is age 21) he/she has the following rights:

1. Right to register and vote;
2. Right to create and maintain financial contracts;
3. Right to sue and to be sued;
4. Right to counsel;
5. Right to be prosecuted as an adult; and
6. Right to choose to continue receiving supports and services or to terminate supports and services; thus residency in any residential setting is voluntary.

Explicit and Implicit Rights

Explicit (fully and clearly defined) rights would include those rights guaranteed us by the Constitution of the United States and by the Constitution of the State of Arizona. These are explicitly worded in the form “you have the right to... ” or “citizens/persons have the right to ...” or “government shall make no law infringing on”

Explicit Rights

The following are examples of explicit rights:

- The right to free speech.
- The right to practice your own religion (or not).
- The right to assembly.
- The right to vote.
- The right to bear arms.
- The right to legal representation.
- The right to due process.
- The right to not incriminate oneself.
- The right to face one’s accusers.
- The right to not be held without charges.
- The right to a trial by jury of peers.
- The right to confidentiality of information and privacy.
- The right to a free and appropriate public education.
- The right to public access.
- The right to non-discrimination due to culture, religion, ethnicity, race, gender, and disability in employment and housing.

Implicit Rights

Implicit (understood though not directly expressed) rights would include those rights we have by implication but are not necessarily stated in the law. Implicit right could include:

Facilitator Note:

These are often rights that we exercise everyday, of which we are not often conscience. These may be protected by implication of other laws (such as criminal). The following are examples of implicit rights.

- To choose
 - clothing,
 - food,
 - entertainment (music, television, movies, books, internet, etc.),
 - job/employment,
 - friends,
 - relationships,
 - bedtime,
 - mealtime,
 - providers of goods and services (e.g., where you shop, who fixes your plumbing, etc.).
- To marry or not.
- To have children or not.
- To smoke or not.
- To say “No.”
- To engage in sexual behavior or not.
- To manage one's own funds and resources.

Facilitator Note:

Understanding the distinction between these rights is important, because for devalued and oppressed groups the implicit rights are often those which are violated and taken away first, because there is not explicit protection. If a group is severely devalued and oppressed, the violation of explicit rights will often follow. Our society has been steadily moving towards making more rights explicit to offer further protections.

Facilitator Note:

Facilitate a discussion about “everyday” situations that may require us to evaluate how to respond while still respecting a person’s rights. For example, a person they are supporting may make the choice to sleep in, causing them to be late to work or school. Just as with anyone else in our society, that is within their rights. If, however, it becomes a health and safety issue, we will need to take additional action. For example, instead of simply sleeping late, a person is laying in soiled clothing/bedding and is refusing to get up or accept assistance for an extended period of time.

While in both these circumstances, it is certainly within the person’s rights to make their own choices, we, as direct care workers, have a responsibility to ensure the health and safety of the person we are supporting. In situations where health and safety are in question, it may be necessary to refer to the Individual Support Plan, Behavior Plan, your supervisor and/or the responsible person for the individual (if applicable) for additional guidance.

D. SELF-DETERMINATION

Self-determination is the right of all people, including those with disabilities, to make choices about their own lives, to have the same rights and responsibilities as everyone else, and to speak and advocate for themselves.

Adapted from Disability Resources:

<http://www.disabilityresources.org/SELF-DETERMINATION.html>

Facilitator Note:

Read, or have a class participant read the definition of Self Determination above.

Ask: Ask the class participants to share why they think it’s important for us to be aware of self-determination. Be sure to include the following topics if they do not come up in the course of discussion.

- Individuals with disabilities have the *right* to make decisions and express preferences.
- Self-Determination allows a person to create a life that is meaningful to them.
- Self-Determination allows a person to have the sense of accomplishment and pride that comes from taking responsibility for one’s own life.

Read: Read or ask a volunteer to read the Five Principles of Self Determination (below).

Activity: Have the participants work in pairs or small groups to read, create, and present a creative representation of the Five Principles of Self Determination to the rest of the group.

PRINCIPLES OF SELF-DETERMINATION

Freedom: The ability for individuals with freely chosen family and/or friends to plan a life with necessary support rather than purchase a program.

Authority: The ability for a person with a disability (with a social support network or circle if needed) to control a certain sum of dollars in order to purchase these supports.

Support: The arranging of resources and personnel – both formal and informal – that will assist an individual with a disability to live a life in the community rich in community association and contribution.

Responsibility: The acceptance of a valued role in a person's community through competitive employment, organizational affiliations, spiritual development and general caring for others in the community, as well as accountability for spending public dollars in ways that are life-enhancing for persons with disabilities (Nerney/Shumway, 1996, pp 4, 5).

Confirmation: Affirming the central role you have in leadership and change.

Self-Determination means that individuals direct the course of their own lives!

E. PERSON FIRST LANGUAGE

Facilitator Note:

Person First Language is a way of communicating respect about the person you support. Person First Language isn't about being "politically correct", but instead, it's about ensuring that we are focused on each individual and his/her unique characteristics.

Language and terminology are continually evolving. The language included in this packet is what is currently recognized as acceptable. You can expect that over the course of your career newer and better terminology will evolve.

The following information from People First Language by Kathie Snow is provided as resource material. Although all the information is included in the Facilitator and Participant Guide, it is not necessary to go through the People First Language information point-by-point. As this information is also covered in the Fundamentals training, use your class time to only emphasize key points, and remind participants of their previous learning experience.

To ensure Inclusion, Freedom, and Respect for all, we must use

PEOPLE FIRST LANGUAGE

by Kathie Snow, www.disabilityisnatural.com

Did you know that people with disabilities constitute our nation's largest minority group (one in five Americans has a disability)? It is also the most inclusive and most diverse group: all ages, genders, religions, ethnicities, sexual orientations, and socioeconomic levels are represented.

Contrary to conventional wisdom, individuals with disabilities are not:

- People who *suffer* from the *tragedy* of *birth defects*.
- *Paraplegic heroes* who *struggle* to become *normal* again.
- *Victims* who *fight* to *overcome* their *challenges*.

Nor are they the *retarded, autistic, blind, deaf, learning disabled, etc.—ad nauseam!*

They are *people*: moms and dads; sons and daughters; employees and employers; friends and neighbors; students and teachers; scientists, reporters, doctors, actors, presidents, and more. People with disabilities are people, *first*.

They do *not* represent the stereotypical perception: a homogenous sub-species called “the handicapped” or “the disabled.” Each person is a unique individual.

The only thing they may have in common with one another is being on the receiving end of societal ignorance, prejudice, and discrimination. Furthermore, this largest minority group is the only one that *any person can join at any time*: at birth or later—through an accident, illness, or the aging process. When it happens to *you*, will you have more in common with others who have disability diagnoses or with family, friends, and co-workers? How will you want to be described and how will you want to be treated?

What *is* a Disability?

Is there a universally-accepted definition of disability? No! First and foremost, a disability descriptor is simply a *medical diagnosis*, which may become a *sociopolitical passport* to services or legal status. Beyond that, the definition is up for grabs, depending on which service system is accessed. The “disability criteria” for early intervention is different from early childhood, which is different from special education, which is different from vocational-rehabilitation, which is different from worker’s compensation, which is different from the military, and so on. Thus, “disability” is a governmental *social construct*, created to identify those entitled to specific services or legal protections.

The Power of Language and Labels

Words are powerful. Old, inaccurate descriptors and the inappropriate use of medical diagnoses perpetuate negative stereotypes and reinforce a significant and incredibly powerful attitudinal barrier. And this invisible, but potent, force—not the diagnosis itself—is the *greatest obstacle* facing individuals who have conditions we call disabilities.

When we see the diagnosis as the most important characteristic of a person, we devalue her as an individual. Do *you* want to be known for your psoriasis, arthritis, diabetes, sexual dysfunction, or any other condition?

Disability diagnoses are, unfortunately, often used to define a person's value and potential, and low expectations and a dismal future are the predicted norm. Too often, we make decisions about how/where the person will be educated, whether he'll work or not, where/how he'll live, and what services are offered, based on the person's *medical diagnosis*, instead on the person's unique and individual needs.

With the best of intentions, we work on people's bodies and brains, while paying scant attention to their hearts and minds. Far too often, the "help" provided can actually cause harm—and *can ruin people's lives*—for "special" services usually result in lifelong social isolation and physical segregation: in special ed classrooms, residential facilities, day programs, sheltered work environments, segregated recreational activities, and more. Are other people isolated, segregated, and devalued because of *their* medical conditions? No.

Inaccurate Descriptors

“Handicapped” is an archaic term (no longer used in federal legislation) that evokes negative images of pity, fear, and worse. The origin of the word is from an Old English bartering game, in which the loser was left with his “hand in his cap” and was said to be at a disadvantage. It was later applied to other people who were thought to be “disadvantaged.” A *legendary* origin of the word refers to a person with a disability begging with his “cap in his hand.” Regardless of origin, this antiquated term perpetuates the negative perception that people with disabilities are a homogenous group of pitiful, needy people! But others who share a certain characteristic are not all alike, and individuals who happen to have disabilities are not all alike. In fact, people with disabilities are more *like* people *without* disabilities than different!

“Handicapped” is often used to describe modified parking spaces, hotel rooms, restrooms, etc. But these usually provide *access* for people with physical or mobility needs—and they may provide *no benefit* for people with visual, hearing, or other conditions. This is one example of the misuse of the H-word as a *generic descriptor*. (The accurate term for modified parking spaces, hotel rooms, etc. is “accessible.”)

“Disabled” is also not appropriate. Traffic reporters often say, “disabled vehicle.” They once said, “stalled car.” Sports reporters say an athlete is on “the disabled list.” They once said, “injured reserve.” Other uses of this word today mean “broken/non-functioning.” *People with disabilities are not broken!*

If a new toaster doesn’t work, we say it’s “defective” or “damaged” and return it. Shall we return babies with “birth defects” or adults with “brain damage”? The accurate and respectful descriptors are “congenital disability” and “brain injury.”

Many parents say, “My child has special needs.” This term generates *pity*, as demonstrated by the usual response: “Oh, I’m *so sorry*,” accompanied by a sad look or a sympathetic pat on the arm. (*Gag!*) A person’s needs aren’t “special” to him—they’re ordinary! Many adults have said they detested this descriptor as children. Let’s learn from them, and *stop using this pity-laden term!*

“Suffers from,” “afflicted with,” “victim of,” “low/high functioning,” and similar descriptors are inaccurate, inappropriate, and archaic. A person simply “has” a disability or a medical diagnosis.

Disability is *Not* the “Problem”

We seem to spend more time talking about the “problems” of a person with a disability than anything else. People *without* disabilities, however, don’t constantly talk about *their* problems. This would result in an inaccurate perception, and would also be counterproductive to creating a positive image. A person who wears glasses, for example, doesn’t say, “I have a *problem* seeing.” She says, “I wear [or need] glasses.”

What is routinely called a “problem” actually reflects a *need*. Thus, Susan doesn’t “have a problem walking,” she “needs/uses a wheelchair.” Ryan doesn’t “have behavior problems,” he “needs behavior supports.” Do *you* want to be known by your “problems” or by the many positive characteristics that make you the unique individual you are? When will people *without* disabilities begin speaking about people *with* disabilities in the respectful way they speak about themselves?

Then there’s the use of “wrong” as in, “We knew there was something *wrong* because...” What must it feel like when a child hears his parents repeat this over and over and over again? How would *you* feel if those who are supposed to love and support you constantly talked about what’s “wrong” with you? Isn’t it time to stop using the many words that cause harm?

The Real Problems are Attitudinal and Environmental Barriers

The real problem is *never* a person’s disability, but the attitudes of others! A change in our attitudes leads to changes in our actions. Attitudes drive actions.

If educators believed in the potential of *all* children, and if they recognized that boys and girls with disabilities need a quality education so they can become successful in the adult world of work, millions of children would no longer be *segregated and undereducated* in special ed classrooms. If employers believed adults with disabilities have (or could learn) valuable job skills, we wouldn’t have an estimated (*and shameful*) 75 percent unemployment rate of people with disabilities. If merchants saw people with disabilities as customers with money to spend, we wouldn’t have so many inaccessible stores, theaters, restrooms, and more. If the service system identified people with disabilities as “customers,” instead of “clients/consumers/recipients,” perhaps it would begin to meet a person’s *real* needs (like inclusion, friendships, etc.) instead of trying to remediate the person’s “problems.”

If individuals with disabilities and family members saw *themselves* as first-class citizens who can and should be fully included in all areas of society, we might focus on what’s really important: living a *Real Life in the Real World*, enjoying ordinary relationships and experiences, and dreaming big dreams (like people without disabilities), instead of living a *Special Life in Disability World*, where services, low expectations, segregation, poverty, dependence, and hopelessness are the norm.

A New Paradigm

“Disability is a natural part of the human experience...”

U.S. Developmental Disabilities/ Bill of Rights Act

Like gender, ethnicity, and other traits, a disability is simply one of many natural characteristics of being human. Are *you* defined by your gender, ethnicity, religion, age, sexual orientation, or other trait? No! So how can we define others by a characteristic that is known as a “disability”?

Yes, *disability is natural*, and it can be *redefined* as “a body part that works differently.” A person with spina bifida may have legs that work differently, a person with Down syndrome may learn differently, and so forth. And the body parts of people *without* disabilities are also different—it’s the *way* these differences impact a person that creates the eligibility for services, entitlements, or legal protections.

In addition, a disability is often a *consequence of the environment*. For example, many children with attention-deficit disorder (ADD) and similar conditions are not diagnosed until they enter public school. Why then? Perhaps when they were younger, their learning styles were *supported* by parents and preschool teachers. But once in public school, if the child’s learning style doesn’t match an educator’s teaching style, the child is said to have a “disability,” and is shipped off to the special ed department. Why do we blame the child, label him, and segregate him in a special classroom? Shouldn’t we, per special ed law, modify the regular curriculum and/or provide supports so he can learn in ways that are best for him? It seems that ADD and other conditions may be “environmentally-induced disabilities”!

When a person is in a welcoming, accessible environment, with appropriate supports, accommodations, and tools, where she can be successful, does she still have a disability? No. *Disability is not a constant state*. The *diagnosis* may be constant, but whether it’s a disability is more a *consequence of the environment* than what a person’s body or mind can/cannot do. We don’t need to change people with disabilities through therapies or interventions. We need to change the *environment*, by providing assistive technology devices, supports, and accommodations to ensure a person’s success.

Using People First Language is Crucial

People First Language puts the person before the disability, and describes what a person *has*, not who a person *is*.

Are you myopic or do you wear glasses?

Are you cancerous or do you have cancer?

Is a person handicapped/disabled or does she have a disability?

If people with disabilities are to be included in all aspects of society, and if they're to be respected and valued as our fellow citizens, we must stop using language that marginalizes and sets them apart. History tells us that the first way to devalue a person is through language.

The use of disability descriptors is appropriate *only* in the service system, at IFSP, IEP, ISP meetings, and/or in medical or legal settings. Medical diagnoses have no place—and *they should be irrelevant*—within families, among friends, and in the community.

Many people share a person's diagnosis in an attempt to provide helpful information, as when a parent says, "My child has Down syndrome," hoping others will understand what the child needs. But this can lead to disastrous outcomes! The diagnosis can scare people, generate pity, and/or set up exclusion ("We can't handle people *like that...*"). Thus, in certain circumstances, *and when it's appropriate*, we can simply share information about what the person needs in a respectful, dignified manner, and *omit the diagnosis*.

Besides, *the diagnosis is nobody's business!* Have individuals with disabilities given us permission to share their personal information with others? If not, how dare we violate their trust! Do *you* routinely tell every Tom, Dick, and Harry about the boil on your spouse's behind? (I hope not!) And we often talk about people with disabilities *in front of them, as if they're not there*. It's time to stop this demeaning practice.

My son, Benjamin, is 23 years old. His interests, strengths, and dreams are more important than his diagnosis. He loves politics, American history, classic rock, and movies; he's earned two karate belts, performed in plays, and won a national award for his *Thumbs Down to Pity* film. Benj has earned his Associate's degree, and he's now working toward his Bachelor's. He has blonde hair, blue eyes, and cerebral palsy. His diagnosis is just one of many characteristics of his whole persona. *He is not his disability, and his potential cannot be predicted by his diagnosis.*

When I meet new people, I don't whine that I'll never be a prima ballerina. I focus on what I can do, not what I can't. Don't you do the same? So when speaking about my son, I don't say, "Benj can't write with a pencil." I say, "Benj writes on a computer." I don't say, "He can't walk." I say, "He uses a power chair." It's a simple, *but vitally important*, matter of perspective. If I want others to know what a great young man he is—more importantly, *if I want him to know what a great young man he is*—I must use positive and accurate descriptors that portray him as a wonderful, valuable, and respected person.

The words used *about* a person have a powerful impact *on* the person. For generations, the hearts and minds of people with disabilities have been crushed by negative, stereotypical descriptors that, in turn, led to segregation, abuse, devaluation, forced sterilization, and worse. We must stop believing and perpetuating the myths—*the lies*—of labels. Children and adults who have conditions called "disabilities" are unique individuals with unlimited potential, like everyone else!

The Civil Rights and Women's Movements prompted changes in language, attitudes, and actions. The Disability Rights Movement is following in those important footsteps. People First Language was created by individuals who said, "We are *not* our disabilities; we are people, first." It's not "political correctness," but good manners and respect.

We can create a new paradigm of disability. In the process, we'll change ourselves and our world—and also generate positive change in the lives of people with disabilities. It's time to care about how our words impact the people we're talking *about*, and to be mindful of the *attitudes and actions* generated by the words we use.

Isn't it time to make this change? If not now, when? If not you, who?

Using People First Language is the right thing to do, so let's do it!

EXAMPLES OF PEOPLE FIRST LANGUAGE

SAY:	INSTEAD OF:
People with disabilities.	The handicapped or disabled.
Paul has a cognitive disability (diagnosis).	He’s mentally retarded.
Kate has autism (or a diagnosis of...)	She’s autistic.
Ryan has Down syndrome (or a diagnosis of...)	He’s Down’s; a Down’s person; mongoloid.
Sara has a learning disability (diagnosis).	She’s learning disabled.
Bob has a physical disability (diagnosis).	He’s a quadriplegic/is crippled.
Mary is of short stature/Mary’s a little person.	She’s a dwarf/midget.
Tom has a mental health condition	He’s emotionally disturbed/mentally ill.
Nora uses a wheelchair/mobility chair	She’s confined to/is wheelchair bound.
Steve receives special ed services	He’s in special ed; is a sped student/inclusion student.
Tonya has a developmental delay	She’s developmentally delayed.
Children without disabilities	Normal, healthy, typical kids.
Communicates with her eyes/device/etc.	Is non-verbal.
Customer.	Client, consumer, recipient, etc.
Congenital disability	Birth defect.
Brain injury	Brain damaged.
Accessible parking, hotel room, etc.	Handicapped parking, hotel room, etc.
She needs . . . or she uses	She has a problem with.../She has special needs.

Keep thinking—there are many other descriptors we need to change!

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Visit www.disabilityisnatural.com for new ways of thinking!

Facilitator Note:

After reviewing the information from the People First Language from Disability is Natural facilitate a discussion with the large group about why Person First Language is important. Be sure to include the following concepts if they do not come up during the discussion:

- A. Person First Language communicates respect
- B. Person First Language communicates value
- C. Person First Language de-emphasizes the disability
- D. Person First Language emphasizes ability!

It's good practice to listen carefully to how language is used in the class. Don't ever put someone on the spot or call them out if they don't use Person First Language perfectly. Instead, listen for correct usage and offer generous praise and positive reinforcement for use of Person First Language!

F. POSITIVE RELATIONSHIPS

Facilitator Note:

Emphasize: Having a positive relationship with the person that you support and their family is critical to your success as a direct support worker!

Having a positive relationship with anyone takes time. It won't happen overnight, but there are some things you can do to ensure that you start off in the right way, and then stay on the right path to maintain that good relationship.

All good relationships share some basic characteristics.

Facilitator Note:

Activity: Ask the group to brainstorm some of the characteristics of positive relationships and write them in their guidebooks. Below are some examples that you may want to include:

Characteristics of Positive Relationships

Trust	Positive Problem solving	Respect
Openness	Communication	Warmness / Fondness
Flexibility	Supportiveness	Listening
Kindness	Compassion	Patience

Facilitator Note:

Tell participants: These aren't all the characteristics of positive relationships, but they will get you off to a good start! On the next page is a place for you to write down other ideas about developing a positive relationship with the individuals that you support.

Facilitator Notes:

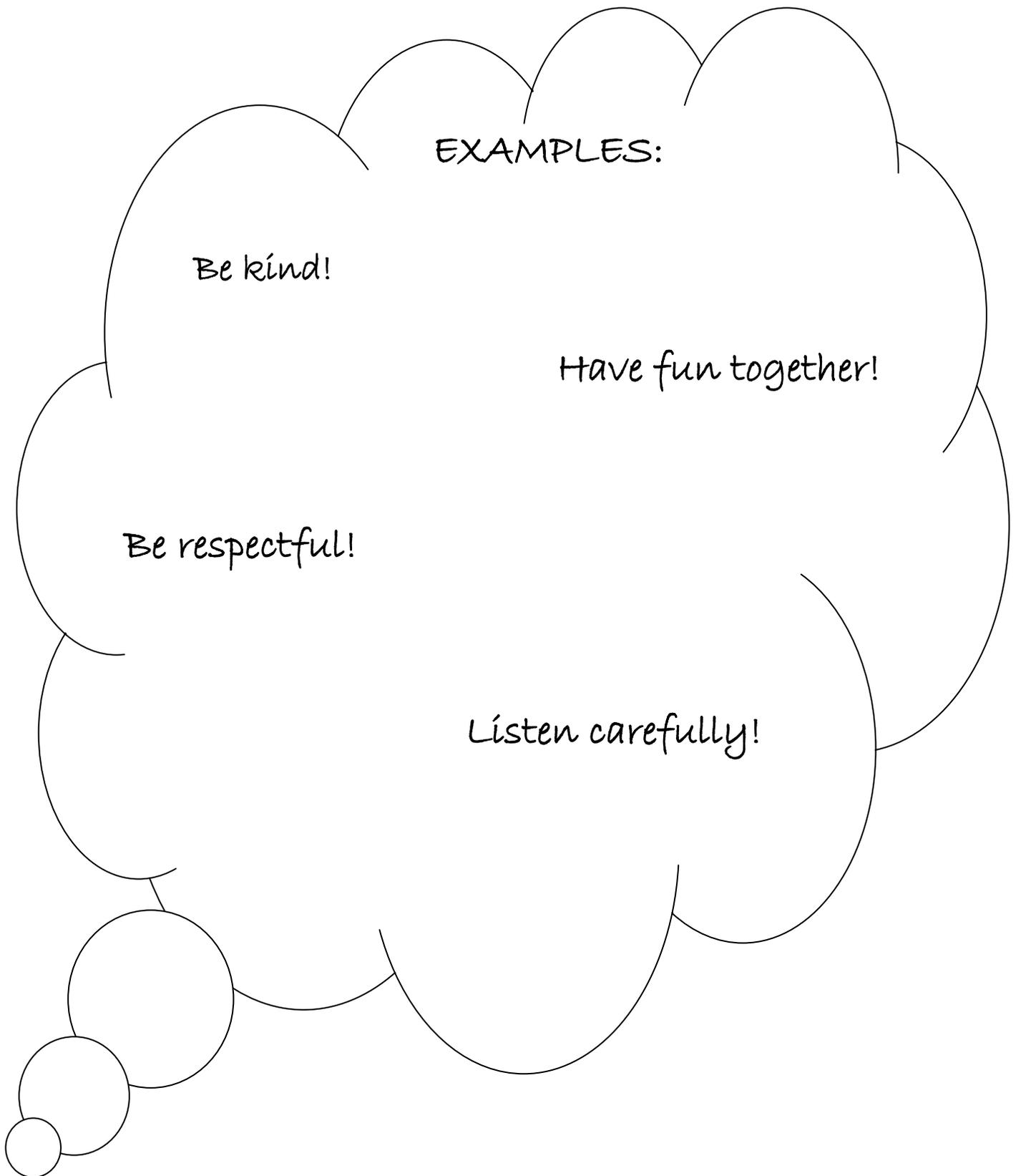
DEVELOPING POSITIVE RELATIONSHIPS (exercise on next page)

There are as many different ways to develop relationships as there are people! The intent of this section is to help the participants identify the core principles involved in developing a positive relationship with anyone.

ASK: Ask the group to work with a partner to brainstorm ways to develop a relationship with the person they are supporting. The participants can write notes in their guidebooks. Below you will find a list of thoughts that you may want to include.

- Be trustworthy – follow through on what you say. Show integrity in your service.
- Be open – don't have any "hidden agendas."
- Communicate clearly and openly. Safeguard personal information.
- Smile! Even challenging tasks can be more fun when you are smiling and cheerful.
- Be flexible. Get the job done, but "go with the flow" as much as possible.
- Talk about things that are interesting to the other person. Find common ground that you can have some discuss.
- Be dependable. Be on-time to work. Complete the tasks that have been assigned to you. Go the extra mile when you can. Leave the individual and the family with the reassurance that in these uncertain times they can count on you!
- Be sincere and honest with the individual and the family. When there are difficult things that need to be said, say them gently and honestly. A strong relationship is based on a sense that the parties involved can be counted on to share truthful information and feelings.
- Be accountable. When you make a mistake, don't make excuses or try to cover it up. Accept responsibility for the error and do what you can to fix it. A sincere apology can help clean up a messy situation.
- Respect and listen to the person that you support and their families.
- Be dedicated and enthusiastic while at work.
- Offer positive feedback on a regular basis.
- If you don't know an answer to a question posed by the individual or their family, be honest. State that you don't know the answer, and that you will take the steps necessary to help them find out the information they need. Be sure to follow through!

DEVELOPING POSITIVE RELATIONSHIPS – BRAINSTORMING



G. PROFESSIONAL RELATIONSHIPS

Facilitator Note:

Introduce this topic by talking about the importance of positive professional relationships at work. You may want to say something like, “Sometimes we get so excited and wrapped up in the dreams and goals of the person that we are supporting that the boundary lines defining our relationship can become blurred.” It is important that we are clear about our role in the lives of the person we are supporting and their families.

ASK:

Ask the group to brainstorm some characteristics of professional relationships, and then personal relationships. Ensure that you include the topics in the table on the next page, (and also included in the participant guide) if they do not come up in the course of the discussion.

ASK:

Ask the group to identify some problems that could come up if there is confusion and ambiguity about the boundaries of our relationship with the person we support.

- Disappointment
- Violation of trust
- Misplaced expectations
- Hurt feelings
- Feelings of being taken advantage of
- Feelings of being used

Family members who are also paid providers may have additional questions about the distinction between personal and professional relationships while they are being paid. Ask for family members in the group to discuss how to balance their close relationship versus their roles as a paid provider.

Expected responses could include:

Place your role as a parent/family member into the background.

Focus on the person and their wants and needs during time you are paid to support them.

PROFESSIONAL RELATIONSHIPS	PERSONAL RELATIONSHIPS
Contribute to the effective operation of the agency that you work for, the state of Arizona and the community at large.	Are strongly influenced by emotion.
Contribute to the quality of life for the person that you are supporting.	Involve all parties sharing personal information and feelings.
Contribute to the quality of life for the family of the person you are supporting.	Contribute to the quality of life for all parties involved.
Are driven by a vision of achieving a common goal.	Are a result of a mutual enjoyment of each other's company.
Are more formal.	Are more casual.
Result in compensation.	Do not result in compensation.
Are appropriate while you are at work.	Are not appropriate while you are at work.

Facilitator Note:

Cornell University's ILR School Employment and Disability Institute has some wonderful information about the topics we have been discussing today. The following information is from Michael Kendrick, "When People Matter More Than Systems," (March 2000 Keynote Presentation for the Conference "The Promise of Opportunity"), posted at the Person-Centered Planning Education Site, Course 1: Introduction to Person-Centered Planning, <http://www.ilr.cornell.edu/edi/pcp/course01.html>.

"Our deep-seated belief systems guide the way in which we interact with other human beings. ... Simply thinking that we are being person-centered does not make us person-centered; it is what we actually do that ultimately reveals our true priorities. It requires a personal commitment to engaging conscious awareness and self-reflection about the relationship between how one feels, thinks, and acts. It is beliefs forming thoughts giving rise to words leading to action that, in turn, create experiences....

Person-centeredness is about intentionally being with people that may or may not include planning. In considering our thoughts about the people with whom we are planning, it is helpful to reflect upon our actions against the following seven touchstones condensed from Kendrick's paper:

- A commitment to know and seek to understand.
- A conscious resolve to be of genuine service.
- An openness to being guided by the person.
- A willingness to struggle for difficult goals.
- Flexibility, creativity, and openness to trying what *might* be possible.
- A willingness to enhance the humanity and dignity of the person.
- To look for the good in people and help to bring it out."

Closing Activity:

As a final activity for the class, you may want to break a larger group into pairs or smaller groups and assign a topic area from the Seven Touchstones listed above. The small group assignment is to "become the teachers" for the topic area(s) they were assigned, and using the information presented throughout the class, and the information from the Cornell University website to teach the topic to the rest of the group. If you have a very small group, you can do the same exercise by only assigning a few of the topics to the group.

- Tell the groups about any resources that may be available to them as they prepare, i.e. the use of whiteboards, newsprint pads, or other available materials.
- Tell the group that everyone must participate in the preparation and presentation of the material.
- Tell the group that they should be sure to include all information on the topic, not just the information from the Cornell University website. Information presented earlier in the class should be included as well as any personal knowledge they have on the topic.

- Remind the group that they need to maintain confidentiality and that presentations must be in good taste and respectful.
- Tell the participants that the length of the presentation is 2-5 minutes (or whatever you decide depending on the length of time left in the class).
- Allowing the group 10-15 minutes to prepare, tell them when presentations will begin.
- While the group(s) are preparing the presentations circulate between the groups providing assistance and feedback as needed.
- As the group(s) present their information, be sure to positively reinforce their efforts! Remember they only had a few minutes to prepare and many people are uncomfortable presenting in front of a group. Make it as positive and safe as possible. If any major points are left out, or if any misinformation is presented, those topics can be discussed between presentations to ensure that everyone learns what is needed.

PRINCIPLES OF CAREGIVING DEVELOPMENTAL DISABILITIES MODULE

CHAPTER 3: ROLE AND REQUIREMENTS OF THE DIVISION OF DEVELOPMENTAL DISABILITIES

FACILITATOR GUIDE

CONTENT:

- A. Role of the Division of Developmental Disabilities
- B. Attendant Care
- C. Documentation and reporting requirements
- D. DCW Activities restricted by the Division of Developmental Disabilities
- E. Supervisory and monitoring requirements for attendant care and housekeeping
- F. Notification to responsible person and agency regarding tardiness or absence

Estimated time for this chapter: 1 hour

Materials needed:

- 1. Facilitator Guide
- 2. Participant Guides
- 3. Forms:
 - a. Pre-Service Agreement (DD-097-2-FF 11-06)
 - b. Attendant Care / Housekeeping Agreement (DD-397-1-FF-3.10)
 - c. Attendant Care / Housekeeping Service Monitoring/Supervision (DDD-1431AFORPF 4-07)

**COMPETENCIES
(TO KNOW OR BE ABLE TO)**

1. Identify responsibilities of the Attendant Care Worker/Direct Care Worker
2. Identify documentation requirements for the Division of Developmental Disabilities.
3. Identify activities that are restricted by the Division of Developmental Disabilities for Direct Care Workers.
4. Explain why notification is critical when you are unable to report to work as scheduled.
5. Identify to whom notification is required when you are unable to report to work as scheduled.
6. Identify how soon notification should occur when you are unable to report to work as scheduled.
7. Identify Direct Care Worker responsibilities related to HIPAA and confidentiality.

KEY TERMS:

Attendant Care	DES – Department of Economic Security
Attendant Care Agreement	Documentation
Confidentiality	Reporting
DDD – Division of Developmental Disabilities	Responsible Person

A. ROLE OF THE DIVISION OF DEVELOPMENTAL DISABILITIES

The Division of Developmental Disabilities (DDD) within the Arizona Department of Economic Security (DES) provides services and programs to people with developmental disabilities. The majority of the Division's services are provided in community settings through in-home services, day programs, community residential services and therapies. The Division serves over 30,000 people with developmental disabilities (as of July 1, 2010).

Facilitator Note:

Of the 30,000, **22,755** consumers are enrolled in the Arizona Long Term Care Services Program (ALTCS). While most Division funded services are delivered through a network of contracted individual and agency providers throughout Arizona, some services such as case management (support coordination) are provided directly by the State.

Each person receiving support from the DDD will have a support coordinator assigned to assist them. The support coordinator, also called case manager, will work to ensure that an individual eligible for services is receiving supports based on the assessed needs.

Support coordinators:

- Gather information to help determine eligibility.
- Develop, with ideas and suggestions from the person and their family, an Individual Support Plan that identifies the supports and services based on assessed needs.
- Assist the person and family in identifying providers for the needed services and supports.
- Monitor the provision and effectiveness of services.
- Provide information about services available from other state and community agencies as well as from private organizations.

Each person receiving supports through DDD will have a personalized **Individual Support Plan (ISP)**. The support coordinator facilitates and monitors a consumer's ISP. Individual Support Plans (ISPs) will be covered in more detail in another session.

Facilitator Note:

Remind the participants that the Mission, Vision, and Values of the Department of Economic Security, Division of Developmental Disabilities were covered during the DCW Training Philosophy module. You may want to facilitate a discussion about what they learned in that section and a reminder of the focus on person-centered supports.

B. ATTENDANT CARE

The Division of Developmental Services (DES/DDD) service description for attendant care is:

Attendant Care is a service that provides a qualified person to assist an individual to attain or maintain safe and sanitary living condition and/or maintain personal cleanliness and activities of daily living. The goal of the service is to assist the individual to remain in his/her home and/or participate in community activities.

Attendant care may be provided in the following settings:

- a. The individual's home.
- b. The individual's community.

The Division of Developmental Disabilities (DDD) provides attendant care for persons who qualify for services. As indicated in the DDD Policy and Procedure, Chapter 600 Services, section 602.1.2 Service Definition (Attendant Care), attendant care may include the following:

- a. Safe and sanitary living conditions may include:
 1. Dusting.
 2. Cleaning floors.
 3. Cleaning bathrooms.
 4. Cleaning windows (if necessary to attain safe or sanitary living condition).
 5. Cleaning oven and refrigerator (if necessary to attain safe or sanitary living condition).
 6. Cleaning kitchen.
 7. Washing dishes.
 8. Changing linens and making beds.
 9. Routine maintenance of household appliances.
- b. Washing, drying and folding consumer's laundry (ironing only if the clothes cannot be worn otherwise).
- c. Shopping for and storing household supplies and medications.
- d. Unusual circumstances may require the following tasks be performed:
 1. Tasks performed to attain safe living conditions:
 - i. Heavy cleaning such as washing walls or ceilings.
 - ii. Yard work such as cleaning the yard and hauling away debris.
 2. Assisting the individual in obtaining and/or caring for basic material needs for water heating and food by:
 - i. Hauling water for household use.
 - ii. Gathering and hauling firewood for household heating or cooking.
 3. Providing or insuring nutritional maintenance for the individual by:
 - i. Planning, shopping and storing food.
 - ii. Cooking foods for nutritious meals.
- e. Assisting with showering, bathing, shampooing, using the bathroom and dressing.

- f. Assisting with transfers to and from wheelchair and/or bed.
- g. Assisting with eating, reminding or encouraging the individual to maintain intake, serving or bringing food to the individual, preparing food for consumption and feeding or assisting the individual with eating.
- h. Assisting with routine ambulation activities.
- i. Assisting with or performing routine nail and skin care.
- j. Assisting with tasks for the comfort and safety of the individuals with movement restrictions (tasks that do not require medical or nursing supervision).
- k. Assisting the individual with special appliances and/or prosthetic devices, if the procedure is routine and well established.
- l. Training the individual, family members and/or friends in personal care tasks as appropriate and available.
- m. Referring for appropriate action all individuals who present additional medical or social problems during the course of the service.
- n. Assisting with self-medication or medication reminders.
- o. Supervising or transporting the individual as a complement to other activities. Supervision and transportation is not a primary goal of Attendant care. Establishing a structured schedule that meets the individual's needs.

Each person receiving DDD services has an Individual Support Plan (or an Individualized Family Service Plan for children under the age of three, enrolled in the Arizona Early Intervention Program) which includes specific information about the duties and tasks to be completed during attendant care services. The information may be recorded on an attendant care agreement, a pre-service provider orientation agreement and/or an assessment form completed by the support coordinator.

Make sure you have received all the information you need to support the person with whom you are working.

Handout:

Provide a copy of the Pre-Service Agreement (DD-097-2-FF 11-06)

Facilitator Notes:

The pre-service provider agreement, although optional, covers essential information the DCW will need to work with the person. Review components of the form.

C. DOCUMENTATION AND REPORTING REQUIREMENTS

Facilitator Notes:

Introduce this section by having the class participants discuss the importance of documentation including the benefit of assuring the information is clear and concise.

DISCUSSION:

To stimulate classroom discussion, ask the following questions and reinforce participation. The intent of this discussion is not to include comprehensive coverage of the topic, but rather, to help the participants to understand how completing the documentation could be helpful to them and the individual they are supporting.

- Have participants brain storm why documentation is important.
- Ask “When do you think you would need to complete documentation?”
- Ask “What things situations regarding health and safety do you think you should document?”
- Ask “How would have written documentation help reduce the possibility of legal liability?”

Why is written documentation important? What do you think you should document?

Written Documentation

DDD requires the documentation of the implementation of all plan outcomes delivered. This includes documenting activities and tasks completed during the delivery of attendant care / housekeeping.

Handouts:

Provide copies of:

- Pre-Service Agreement (DD-097-2-FF 11-06)
- Attendant Care / Housekeeping Agreement (DD-397-1-FF 3.10)

Facilitator Note: Discuss the forms and each of the following examples.

Examples of Documentation for Attendant Care:

- Medical Issues
 - Seizure activity
 - Signs of illness
 - Concerns with skin integrity
 - Injury
 - Blood sugar levels

- Change in behavior
 - Sudden outbursts
 - Unsafe behavior, such as self injury
 - Sadness or depression

- Activities / tasks completed
 - How the person ate
 - Assistance with hygiene
 - Repositioning schedule
 - Assistance with self-administration of medication (date and time(s))
 - Activities in the community
 - Housekeeping tasks

- Incident reports
 - All serious incidents must be reported to the Division. See the Incident Reporting chapter for more detail.

- Attendant Care Monitoring (Initial and Quarterly)
- Documentation of any special monitoring requirements identified in the Support Plan or requested by the responsible party.

Other documentation:

Recording time and contact hours provided on behalf of the consumer.

- Timesheets

Note: The Division of Developmental Disabilities no longer requires submission of monthly documentation of the activities completed while attendant care is provided. However, maintaining ongoing documentation and records of attendant care and housekeeping services provided to each individual continues to be a requirement.

D. DCW ACTIVITIES RESTRICTED BY THE DIVISION OF DEVELOPMENTAL DISABILITIES

As indicated in Department of Economic Security/ Division of Developmental Disabilities (DES/DDD) Policy and Procedures Manual, Chapter 600 Services, Section 602.1.6 the following activities are prohibited under Attendant Care.

Exclusions (Attendant Care)

- Providers of Attendant Care shall **not** perform the following tasks:
 - Cleaning up after parties.
 - Cleaning up several days of accumulated dishes.
 - Preparing meals for the *whole* family.
 - Routine lawn care.
 - Major carpet cleaning.
 - Caring for household pets such as walking the dog (unless it is a service animal).

- Attendant Care providers shall not provide cleaning to areas of the home not used by individuals, e.g., parents' bedroom or sibling's bathroom.

- Providers shall not perform skilled medical tasks/nursing tasks. Examples of prohibited skilled medical tasks include:
 - Insulin injections.
 - Nasogastric (NG) tube feeding.
 - Deep suctioning.

Other Restricted Activities

- Caring for siblings or other children in the home.
- Bringing one's own children to the worksite.
- Falsifying any documents; for example, timesheets.

E. SUPERVISORY AND MONITORING REQUIREMENTS FOR ATTENDANT CARE AND HOUSEKEEPING

Minimum requirements are:

- The provider agency must make an initial on-site supervisory visit within five days after service starts. The provider agency representative must speak with the consumer/or representative regarding the quality of care, delivery of services and education of the consumer/or their representative. They will also discuss the need to call the agency provider if concerns develop between visits by the supervisor and/or support coordinator.
- A follow-up site visit is required at 30 days.
- A 60 day visit is required if issues are identified. Otherwise these ongoing visits shall be made every 90 days thereafter.
- At least one supervisory visit is required for each direct care worker within the first 90 days of the hire date. The direct care staff must be present.
- The provider agency will also assess the direct care worker's competency in completing the assigned tasks/duties. The supervisor must assure that the DCW is completing the duties/tasks according to the training provided to the DCW.
- Provide copy of and review:

Attendant Care / Housekeeping Service Monitoring / Supervision (DDD-1431AFORPF 4-07)

F. NOTIFICATION TO RESPONSIBLE PERSON AND AGENCY REGARDING TARDINESS OR ABSENCE

Facilitator Notes:

Introduce this section by explaining:

- Risk management and prevention strategies are an important component of providing supports to people who require assistance. When an individual receives critical supports (bathing, toileting, dressing, feeding, transferring to or from bed or wheelchair and assistance with similar activities) a back-up plan of alternate providers **MUST** be developed to address potential risks in the event the provider (DCW) does not arrive to provide the needed services. From <https://www.azdes.gov/ddd/about.asp>

ACTIVITIES:

Choose one or more of the following activities and have the participants make their notes in their guidebooks. Whatever activity you choose, ensure that the discussion includes the impact of not receiving critical supports, including the possible negative effects on their physical health and well-being, emotional health and well-being and their relationship with you and all future support providers.

- Have class participant's brain storm what the consequences might be for the consumer if the DCW did not notify the appropriate parties as soon as possible when unable to report to work as scheduled.
- What are ways DCW can make sure they have the needed contact information available to contact the family/individual and agency.
- Describe how an individual receiving support might feel if a DCW does not show up for a scheduled shift.

NOTES: What can happen if the DCW does not arrive as scheduled?

Facilitator Notes:

In closing this topic, emphasize the following information:

The consumer or primary caregiver chooses how quickly a replacement caregiver will be needed if the scheduled Direct Care Worker becomes unavailable.

When a provider agency is authorized by DDD to provide a critical service (attendant care, respite, or housekeeping), a back-up plan that identifies a replacement caregiver is required in the event that a scheduled provider does not show up to work as scheduled for any reason. The consumer/family has the right to a replacement provider within 2 hours if they choose.

For this reason, it is critical for you, the DCW, to notify the consumer, family and your employer as soon as possible when you are unable to work as scheduled so a replacement can be identified within the required timeframe.

PRINCIPLES OF CAREGIVING DEVELOPMENTAL DISABILITIES MODULE

CHAPTER 4: SUPPORT PLANNING

FACILITATOR GUIDE

CONTENT:

- A. Goal Planning
- B. Individual Support Plans
- C. Support Plan Basics
- D. Roles and Responsibilities of Team Members

Estimated time for this chapter: 1 hour

Needed Materials:

1. Facilitator Guide
2. Participant Guides
3. Blank Individual Support Plan documents for each person attending

Competencies:

1. Explain the purpose of the Individual Support Plan (ISP) or other Division of Developmental Disabilities planning documents.
2. Identify two ways a DCW is involved in the team approach in plan development.
3. Name three parts of the planning documents that help inform the DCW about the person receiving support.

Key Terms:

Back-up plan

Risk assessment

Individual Support Plan (ISP)

Short term goal

Long Term goal

Team assessment

A. GOAL PLANNING

Facilitator Note:

Discuss the following information:

Support planning is a process that we use to help identify the things that a person wants to achieve, the skills that need to be learned, and the barriers that need to be overcome to achieve that dream, and a step-by-step plan to help get them there. It's not really different than the type of goals setting that we all do.

Activity: Have participants turn to the goal planning page in their handout.

Use the instructions for this exercise on the following pages.

Long-term goals

A long-term goal is anything that you want to accomplish in your life. Make it specific, i.e. buy a house, get a degree, lose 25 pounds, etc.

My long-term goal:

Short-term goals

A short-term goal is a milestone, or major "chunk" of the long term goal that you will need to accomplish in order to achieve your long-term goal, i.e. have a credit score of 600, or identify the part of town you want to live in.

My short-term goals:

First steps

First steps are the things that you can do today, or in the very near future, to reach your milestones (short-term goals), and eventually your long-term goal, i.e. open a bank account or get a gym membership.

My First Steps:

Barriers

Barriers are anything that may slow you down, or prevent you from reaching your Goals i.e. poor health, lack of budgeting skills

My barriers:

Facilitator Instructions - Goal Planning Exercise:

Complete the activity by following each of these steps:

- Using the handout provided identify one measurable long-term goal that you have. A good measurable goal might be something like “I want to have my bachelor’s degree,” or “I want to buy a car,” or “I want to be married with 2 children.” An example of a goal that is *not* measurable would be, “I want to be a nicer person,” or “I want to be smarter.” To be measurable, there must be a specific outcome that can be seen, heard, or otherwise measured. For “I want to be a nicer person” it could become “I want to have 4 friends that I visit at least 1 time per week” (being with friends can be seen and measured), for “I want to be smarter” it could be, “I want to complete an expert level Sudoku!” (Completing a Sudoku puzzle can be seen and measured.)
- What are some short-term goals or milestones that you will need to achieve to reach your goal? Note these on the handout provided.
- Next, write down some steps that you can take today to move toward your goals.
- Finally, what barriers could keep you from reaching your goals?

Goal Planning Example: Facilitator’s should model one example on a whiteboard or newsprint pad step-by-step. You may choose to use your own example, or demonstrate an example from a long-term goal provided by the group. Below you will find an example of one of the many ways this exercise could be completed.

Long-term goal:

- Buy a new car

Short-term goals:

- Good credit
- Savings
- Driver’s license

First steps:

- Pay bills on time
- Put \$25.00 per paycheck in the bank
- Study for drivers test 10 minutes each day

Barriers:

- Overspending on fast food and entertainment / Create a budget
- Habit of paying bills late / Write due dates on calendar
- Lack of time to study for drivers test / schedule 10 minutes each day during lunch for studying

Facilitator Note: Begin by explaining your long-term goal, in this example, buying a car. Explain the short-term goals that will need to be accomplished to reach your long-term goal, in this case having good credit, having some money saved, and having a driver's license. Go on to explain that to reach these short-term goals, and ultimately the long-term goal, there are things that will need to be done on a regular basis and skills that need to be acquired. For example, pay bills on time to improved credit score, put money in bank each week to save toward car payment, and study for driving test to get a driver's license.

You may want to comment that these first steps are the equivalent of the outcomes / objectives you will be discussing later in the class.

Go on to discuss the things that could prevent you from reaching your goals like choosing to spend your money on other things, poor bill paying habits, or lack of time to study for the driving test. Identify some solutions for these barriers, creating and sticking to a budget, writing due dates for bills on a calendar, setting time aside each day to focus on the driving test manual etc.

You may want to facilitate a discussion with the participants and have them identify steps to address each of the barriers. You also may want to comment that these actions would become either outcomes / objectives for the individual or they could become team agreements or assignments if this were a real ISP.

Tell the participants that they have just completed a process that is very similar to the ISP process. The purpose of the ISP is to identify the individual's goals, the steps that will be necessary, any barriers or obstacles they may face, and how the individual and the team will address those obstacles.

B. INDIVIDUAL SUPPORT PLANS

The Support Plan describes the person's goals and plans and what works for the person. This can include:

- Likes and dislikes.
- Abilities and special needs of the person in areas like daily living skills.
- Medical issues, communication and movement issues.
- Social and family supports.
- Medication assistance needs, potential health and safety risks.
- Services and supports a person will receive.

The purpose of support planning is to ensure that everyone is working together to achieve the goals identified by the individual being supported. The planning document becomes the roadmap for how services and supports are delivered.

The Support Planning Team:

The support plan is developed during a team meeting that includes, most importantly, the person being supported. The team will also include all the people that are important to the person and may include:

- Person being supported.
- Parent or guardian.
- Support coordinator (case manager).
- Direct care workers.
- Friends, family, advocates, neighbors and others as invited by the individual and their family.

During this meeting, one or more long-term goals will be identified that are important to the person and his or her family. Services, supports, team agreements and assignments, specific outcomes and other action items will then be identified based on this long-term goal.

All Support Plans:

- Are individualized.
- Are developed with the person and, when appropriate, his/her family.
- Documents the individual's strengths, needs, and resources.

C. SUPPORT PLAN BASICS

Facilitator Note: Hand out a blank Individual Support Plan for the class to look at. Take a few minutes to point out the following specific areas in the Individual Support Plan document.

A basic support plan includes some critical information! Be sure to review this document, and the information listed below, in particular, for each individual that you support!

Preferences and Vision of the Future

The vision of the future section identifies the person's 3-5 year goals, such as relationships, community involvement, work, education, where the person wants to live. This is based on the person's goals and should be in the person's own words.

The preferences section should give the Direct Care Worker information about what motivates the individual, activities the individual enjoys, and what to avoid.

Team Assessment Summary

The team assessment summary provides the Direct Care Worker with an overview of the individual's strengths and support needs in areas of health, learning, communication, social skills, self-care, family, etc.

Support Information, includes medication, adaptive equipment, and behavioral health needs. Information in this section changes rapidly, so be sure to check for updates.

Risk Assessment

The risk assessment identifies areas of health and safety the Direct Care Worker needs to be aware of. Some examples include history of seizures, self-abuse, dietary needs, choking, etc.

Back-up Plan

The back-up plan will list names and contact numbers if a Direct Care Worker is unable to provide a contracted support, and timeframes for filling the need.

The areas listed above are some examples. Attendant care tasks, accomplishments, team agreements, and all other plan documentation will also support the Direct Care Worker.

- Each individual receiving services through DES/DDD has an individualized plan, Individual Support Plan (ISP), or an Individualized Family Service Plan (IFSP), used for children 0-3 years of age and their families. They may also have a Person Centered Plan (PCP).
- The support plan provides important information you need to do your job.
- The support plan documents the person's likes, dislikes, individualized needs, and goals.
- The support plan is reviewed through quarterly and annual team meetings, and ongoing monitoring by the Support Coordinator.

Facilitator Note: Ongoing monitoring includes progress reports, reviewing attendant monitoring, and incident reports.

Individuals are in charge of their ISP and entitled to make decisions and choices about their lives, with the least amount of assistance necessary from family, guardians and support systems.

Not all supports need to be written in formal support plans. The team should also discuss informal supports for the person to participate actively and in a meaningful way each day.

Informal supports can be wide and varied. It may be access to a cell phone, so a person can be alone in the community or stay in touch with people important to them. It may include faith communities, natural supports, social groups, online supports, etc. The support planning teams should be creative and flexible in identifying the best ways to help a person be successful!

D. ROLES AND RESPONSIBILITIES OF TEAM MEMBERS

Individual

The individual receiving support is central in the development of the plan. The person is there to talk about choices, hopes, dreams, and any potential barriers. Regardless of any potential participation barriers, including age, cognitive development, and communication ability, this meeting is for the person. The plan belongs to the individual. Teams may need to be creative to accommodate the person's needs and preferences.

People important to the individual including:

Family

Depending on the needs of the individual, the family may play a very large role in the planning process. In fact, if the plan is an IFSP, the planning process focuses on the family, not just in the individual. For other plans, family involvement will vary from person to person. If family members are legally responsible, they must be a part of the planning team. If the person is an adult and legally responsible for himself or herself, it's the person's choice who they wish to invite. Participants in the support planning process could include:

- Family members
- Significant Others/Spouse
- Friends
- Other Advocates

Other Team Members

Other team members contribute in any way that reflects the best interests of the person being supported. This could include sharing assessment information, advocating, making recommendations and determining the specific supports and services that will help the person achieve their goals.

Direct Care Workers

Direct Care Workers support people with developmental disabilities to work toward their goals and help to meet their daily needs. The support plan is the person's map directing you to where the person wants to go and the steps needed to get there.

Before the meeting:

- Get to know the person and develop a respectful relationship.
- Help the person think about what he/she wants to express at the meeting.
- If need be, think of ways to help the person participate in the meeting.
- Prepare to discuss progress, challenges, and changes since the last team meeting.

During the meeting:

- Be professional.
- Be a positive, active participant.
- Speak up and share what you have learned about the person.
- Support the person's participation.
- Focus on the person's desires, capabilities and talents.
- Be an advocate.

After the meeting

- Implement the supports outlined in the plan.
- Carry out the actions you are responsible for.
- Communicate with other team members.
- Complete required documentation.

Facilitator Note:

Wrap up the class by asking if there are any questions and thanking the participants for attending. If time allows you may want to do a summary or more in-depth review of the information covered during the class. If you will be doing additional training following this module, this would be a good time for a break.

PRINCIPLES OF CAREGIVING DEVELOPMENTAL DISABILITIES MODULE

CHAPTER 5: ABUSE AND NEGLECT

FACILITATOR GUIDE

CONTENT:

- A. Introduction
- B. Reporting abuse and neglect
- C. Definitions of abuse and neglect
- D. Responding to abuse and neglect
- E. Additional resources

Estimated time for this chapter: 2.5 hour

Needed Materials:

1. Facilitator Guide
2. Participant Guides
3. 3 prepared pieces of newsprint paper

COMPETENCIES:

1. Identify physical signs and symptoms of suspected abuse and/or neglect.
 2. Identify behavioral signs and symptoms of suspected abuse and/or neglect.
 3. Identify environmental signs that may be related to suspected abuse and/or neglect.
 4. Identify what information is necessary for reporting suspected abuse and neglect.
 5. Explain what you need to do if you suspect abuse or neglect.
-
-

KEY TERMS:

Abuse

Exploitation

Abusive treatment

Mandatory reporting

Adult Protective Services (APS)

Neglect

Child Protective Services (CPS)

Vulnerable

A. INTRODUCTION

Facilitator Note:

Because people with disabilities have been treated poorly by society throughout history, we spend extra time making sure that Direct Care Workers understand the importance of recognizing abuse, neglect and exploitation (taking advantage of a person for personal gain).

Some children and adults with developmental disabilities are vulnerable. This requires support providers and families to be aware of signs and symptoms of maltreatment and neglect.

Characteristics that increase a person's vulnerability include:

- Powerlessness
- Dependency
- Compliance
- Inability to prevent, escape, or disclose abuse
- Lack of body ownership
- Desire to fit in
- Denial or failure to recognize signs of abuse

People with developmental disabilities are more likely to be abused and neglected than the general population. People with disabilities are more likely to experience:

- Multiple forms of abuse and neglect
- Multiple perpetrators of abuse
- Abuse and neglect over a long period of time
- Lack of appropriate health care
- Inappropriate use of prescribed medications (use of medication to subdue or overmedicate)
- Misleading statements and behavior by support providers
- Using the disability to explain or minimize abuse
- Blaming injuries on the child (adult)
- Empathy for the support provider/caregiver clouds concerns for child(adult)
- Concerns and reports overruled by authority figures
- Multiple contacts with health care providers and other professionals, with failure to recognize or respond to abuse
- Ignoring, misunderstanding, or misinterpreting signs and symptoms of abuse

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B. REPORTING ABUSE AND NEGLECT

All health care providers, social workers and Direct Care Workers have an ethical and legal responsibility to report to Child Protective Services (CPS), Adult Protective Services (APS), or law enforcement any suspected abuse, neglect, or exploitation. In addition to your mandated reporting responsibility, any concerns you have about the care or treatment of a person you are working with must be reported to your employer and to the Division of Developmental Disabilities.

Facilitator Note: Complement this material with the section on reporting in Fundamentals, chapter 2 Legal and Ethical Issues.

The Mandatory Reporting Laws of the State of Arizona

(Arizona Revised Statute 13-3620)

“Any person who reasonably believes that a minor is or has been the victim of physical injury, abuse, child abuse, a reportable offense or neglect that appears to have been inflicted on the minor by other than accidental means...shall immediately report or cause reports to be made of this information to a peace officer or to Child Protective Services in the Department of Economic Security, except if the report concerns a person who does not have care, custody or control of the minor, the report shall be made to a peace officer only.”

(Arizona Revised Statute 46-454)

Duty to report abuse, neglect and exploitation of vulnerable adults;
duty to make medical records available; violation; classification

A physician, registered nurse practitioner, hospital intern or resident, surgeon, dentist, psychologist, social worker, peace officer or other person who has responsibility for the care of a vulnerable adult and who has a reasonable basis to believe that abuse or neglect of the adult has occurred or that exploitation of the adult's property has occurred shall immediately report or cause reports to be made of such reasonable basis to a peace officer or to a protective services worker. The guardian or conservator of a vulnerable adult shall immediately report or cause reports to be made of such reasonable basis to the superior court. All of the above reports shall be made immediately in person or by telephone and shall be followed by a written report mailed or delivered within forty-eight hours or on the next working day if the forty-eight hours expire on a weekend or holiday.

C. DEFINITIONS OF ABUSE AND NEGLECT

Abusive Treatment:

Abusive Treatment includes, but is not limited to:

- a. **Physical abuse** by inflicting pain or injury to an individual. This includes hitting, kicking, pinching, slapping, pulling hair or any sexual abuse (including inappropriate touch).
- b. **Emotional abuse** which includes ridiculing or demeaning an individual, making derogatory remarks to an individual or cursing directed towards an individual.
- c. **Programmatic abuse** is the use of procedures or techniques, which are not part of the support/service plan or are prohibited.

Facilitator Notes:

Abuse can include anything that intentionally harms the person being supported. This can include physical harm like hitting, pinching, kicking, slapping, pulling hair, sexual assault. It can also include emotional harm like name calling, swearing at a person, demeaning them or making them feel bad about themselves. Abuse can also occur when a direct care worker violates the Article 9, for example, refusing to give a person an afternoon snack because the individual did not eat all their lunch.

Neglect:

Neglect means a pattern of conduct without the person's informed consent resulting in deprivation of food, water, medication, medical services, shelter, cooling, heating, or other services necessary to maintain physical or mental health.

It also includes:

- a. Intentional lack of attention to physical needs of the individual such as using the bathroom, bathing, meals and safety.
- b. Intentional failure to report medical problems or changes in health condition to immediate supervisor or nurse.
- c. Sleeping on duty or abandoning work station (including leaving the individual unsupervised).
- d. Intentional failure to carry out a prescribed treatment plan for the individual.
- e. Failure to provide required supervision, propping a pool fence open, not following traffic laws, or taking other unnecessary risks.

Facilitator Notes:

Neglect occurs whenever a direct care worker, or other person responsible for a child or vulnerable adult, fails to meet that person's needs. Examples of neglect could include failing to meet nutritional needs, not following medical orders or ISP directives, falling asleep on the job, not assisting with going to the restroom or hygiene needs, not following the Article 9 guidelines (not following the attendant care agreement, not meeting safety needs, not providing required supervision, propping the pool fence open, not following traffic laws, or taking other unnecessary risks).

Exploitation happens when a direct care worker or other person responsible for the individual takes or uses that person's money, possessions, or other resources for their own benefit.

Facilitator Note: State that abuse and neglect can take many forms and can sometimes be difficult to identify.

ACTIVITY:

Signs and Symptoms of Abuse and Neglect

Before class, prepare three large pieces of newsprint pad or other large paper by labeling the top of each as follows:

- Physical Signs
- Emotional/Behavioral Signs
- Environmental Signs

Hang the papers on the wall, put them on stands, or in some other way make them accessible to the class.

Have the class work in small groups or rotate as individuals through the three "stations" brainstorming and writing on the papers as many examples of signs of abuse and/or neglect as they can. You may need to give an example or two to get the groups started.

After the groups or individuals have had a chance to rotate through each of the newsprint pads adding their ideas, review the information gathered with the larger group. Be sure to provide plenty of positive feedback for answers provided. If they do not show up on the papers, you will want to include the examples provided below.

D. RESPONDING TO ABUSE AND NEGLECT

Facilitator Note:

Review one or more of the Abuse and Neglect Scenarios with the class. (The scenarios are in the Instructor Resources section in the back of this chapter). This activity can be done one-on-one, or if you have a larger group you can have them work in pairs or small groups to review the scenario. Ask the class to identify the different signs of abuse or neglect within the scenario(s).

If working in pairs or groups, debrief each scenario out loud with the larger group. Be aware of the time, but spend adequate time to ensure that everyone in the class is able to identify the characteristics of the various types of abuse.

Transition to the next section by saying something like, “as mandatory reporters, we have certain responsibilities when we have a suspicion of abuse or neglect”. You may want to ask the group to share what they already know about mandatory reporting.

Reporting abuse and neglect

All known or suspected abuse and/or neglect *must* be reported to:

Adult Protective Services (if the person is 18 years old or older)
1-877-767-2385

Child Protective Services (if the person is 17 years old or younger)
1-888-767-2445

The Division of Developmental Disabilities (DES/DDD) written report in the form of an Incident Report (see the chapter on Incident Reports) must be completed.

Failure to report abuse or neglect can also be considered abuse with consequences that could include:

- Termination
- Fine
- Imprisonment

Facilitator Note:

Any suspected abuse or neglect must be reported immediately to Child Protective Services (if the individual is under the age of 18) or Adult Protective Services (if the

individual is 18-years-old or older). It is your responsibility by law, meaning it is mandatory for you, to report directly **or to assure that** a report is made to Child Protective Services (CPS) or Adult Protective Services (APS) if you suspect that a person you support is being abused, neglected, or taken advantage of (exploitation). An incident report to the Division of Developmental Disabilities must also be completed. Additional follow-up may be requested.

It is strongly recommended and preferred that Direct Care Workers make immediate reports of suspected abuse or neglect directly to CPS, APS, or law enforcement. If the allegations are reported to an agency supervisor, the supervisor can call in the mandatory report; however it is still the responsibility of the Direct Care Worker to make sure the report is made as soon as possible.

If abuse or neglect is suspected and/or observed, it must be reported immediately to:

**The DES/DDD Support Coordinator
Child Protective Services (children under the age of 18)
or Adult Protective Services (adults 18 years of age or older).**

This includes abuse, physical injury, denial or deprivation of medical surgical care to a minor or abuse neglect or exploitation of an incapacitated or vulnerable adult

**Child Protective Services 24 Hour
Reporting Number
1-888-767-2445**

**Adult Protective Services 24 Hour
Reporting Number
1-877-767-2385**

As a mandatory reporter, it is the responsibility of the Direct Care Worker to assure a report is made to Child Protective Services or Adult Protective Services depending on the age of the individual.

What to Report	
Abuse or Neglect of a Child	Abuse or Neglect of a Vulnerable Adult
Name of the child	Name of the adult
Address of the child	Name of responsible person – if it is someone other than the individual
Name of parents or the responsible person	Adults age
Age of the child	Nature and extent of their vulnerability
Nature and extent of injuries or neglect	Nature and extent of injuries, neglect or exploitation
Any evidence of previous injuries or neglect	Other information that may be helpful in investigating the case
Any other information that may be helpful in investigating the case	Other information as requested
Other information as requested	
When to Report	
Any time you are concerned for the immediate health and safety of the individual you are supporting, call law enforcement!	
IMMEDIATELY report to a local Child Protective Services Worker	IMMEDIATELY report to a local adult protective services worker.
Submit written report (serious incident report) to the Division of Developmental Disabilities within one working day.	Submit written report (serious incident report) to the Division of Developmental Disabilities within one working day.

Steps to take if you suspect abuse and/or neglect

If you know or suspect that one of the individuals you are supporting is being abused or neglected, here are the steps to follow:

Protect the person.

Facilitator Note: Protecting the person does not mean physically intervening with another person. The Direct Care Worker must take care not to put themselves in a dangerous situation.

Protecting the person may include calling the police to handle the situation. It may also include staying with the person until their safety is ensured.

Report it verbally to your supervisor.

Facilitator Note: The verbal report is a courtesy to your employer and does not meet the intent of the mandatory reporting requirement.

Write an Incident Report.

Facilitator Note: This is a good time to hand out or show an incident report form. The next section will cover all the information that should be included in the report. You will want to include a discussion about how the incident report form fits in the reporting continuum of communication to the Division of Developmental Disabilities, the responsible person, and CPS or APS for meeting the mandatory reporting requirements.

Participate in the investigation process as requested.

Facilitator Note: Participating in the investigation includes sharing what you know with your agency, the Division of Developmental Disabilities, and Child or Adult Protective Services. It also means not talking about the alleged abuse or neglect with other people who are not part of the investigation team.

Remember, abuse and neglect are prohibited in all services and programs operated or supported by the Department of Economic Security, Division of Developmental Disabilities, and anyone doing so is subject to dismissal and prosecution.

We, as Direct Care Workers, have additionally been identified by law as mandatory reporters. That means we have a legal obligation to report any reasonable suspicion that abuse, neglect or exploitation are occurring.

IMPORTANT! Your job is to *report!* You are not the person doing the investigation! By reporting your concerns, you have done your job. There is no need for you to go back to do follow-up regarding the allegations. In fact, you are not allowed to do any investigating! Although it may create temporary turmoil or upset, the benefit to the person you support is the top priority. You have done your job, and should feel confident that you are doing your part.

E. ADDITIONAL RESOURCES FOR PARTICIPANTS

Physical signs of abuse or neglect can include:

- Bruises
 - On different parts of body
 - In unusual shapes (circling the arm or in the shape of a handprint or object)
 - Unusually large
 - Frequent, high numbers
 - In unusual places
 - In different stages of healing
- Burns
 - Unusual shapes
 - Unusually large
 - Unusual places
- Cuts / Abrasions
- Fractures
 - Any bone breakage of the face, jaw, or skull should be regarded as suspicious as should spiral fractures of the long bones
- Poor hygiene
- Vaginal/Rectal pain
- Medication issues
- Dehydration
- Malnutrition
- Sunburn
- Frequent illness/stress related illnesses
- Untreated long term illness
- Skin infections
- Sexually transmitted diseases in a person not known to be sexually active
- Pregnancy in a person not known to be sexually active
- Malnourishment
- Failure to thrive
- Frequently dirty
- Body odor
- Rotting teeth

Behavioral signs of abuse or neglect can include:

- Avoidance of significant family, friends or care workers
- Delays in seeking treatment
- Regression / Deterioration of skills
- Incontinence (lack of bladder control)
- Fear of a specific person or location
- Fear of being touched
- Flinching / Startle response
- Significant change in interest in sexual acts
- Changes in eating habits
- Changes in sleeping habits
- Withdrawal
- Depression
- Expression of poor self esteem and self image
- Overly critical of self and others
- Extremes in behavior
- Sudden unexplained changes in behavior
- Reporting of abuse and/or neglect
- Running away
- Extremes in relationships
- Poor peer relationships
- Not able to be consoled
- Vaguely expressed fear of being in the abusive environment
- Perfectionism
- Loss of joy, fun
- Promiscuity, prostitution
- Wearing multiple layers of clothing
- Violent symbolic play, artwork, and/or storytelling

Environmental signs of abuse or neglect can include:

- Lack of necessities like food, water, heating, cooling
- Lack of utilities
- Lack of adequate space
- Lack of ventilation
- Animal or insect infestation
- Unsafe conditions due to lack of maintenance i.e. bare wires, uncovered outlets, broken pipes etc.
- Filth including garbage, human or animal waste, rotten food, etc.
- Clothing is filthy and in disrepair
- The individual has responsibility far beyond what is fair and developmentally appropriate
- Caregivers cannot be located in cases of emergencies
- Individual fails to attend schools or programs without explanation
- Bad odor in the environment
- Animals in the environment are neglected and/or abused

INSTRUCTOR RESOURCES

Scenarios:

Chelsea has a seizure disorder. Her family is very disorganized and frequently forgets to give her the prescribe seizure medications. Sometimes the prescription is not filled on time. She has frequent seizures and as a result has facial scars and missing teeth. A month ago, you mention to the family that maybe Chelsea should see her doctor to have her medication levels checked. The family agreed but has not taken her yet. Today you had to call 911 when she had a seizure.

Chelsea's situation represents medical neglect.

Steven is a 15 year old with Down syndrome. As a result of prior abuse, he has severe behavior outbursts that include hitting and biting others. He takes Clonidine, and one of its side effects is sedation. You notice his caregiver has been giving him twice the dosage because he becomes passive and sleeps most of the time.

Steven's situation represents misuse of prescribed treatments.

Joey, age 4, has fetal alcohol syndrome and developmental delays. You saw a bruise on his face and when you asked the caretaker what happened she went into great detail about the effects of fetal alcohol syndrome and how he constantly runs into things and hurts himself. She did not explain how the bruise on his face occurred.

Joey's situation is one where the caregiver used the child's disability to explain the injury.

Randy is a twenty five year old with cerebral palsy who lives with his older brother. You just started working with him. You notice the house is very dirty and that there is no food in the refrigerator or cupboards. It looks like Randy had not been dressed or out of his bed for a long time. He doesn't have any clean clothes. While helping Randy, you see that he has a very bad pressure sore. After Randy gets dressed, you ask him if he wants to go to the grocery store. Randy tells you that his brother takes his monthly check and that he never has any money. You ask Randy's brother for some money to buy groceries and he asks you to leave and never come back.

Randy's situation is one of possible neglect and exploitation.

Sandy is a 15 year old woman diagnosed with autism. She uses gestures and vocalizations to communicate. For a while, you have noticed that Sandy appears to be afraid and does not want to be touched when you are helping with her shower. For the past few days, she refuses to get into the shower at all. While helping her change, she points to herself and starts crying. You are not comfortable asking the family what is going on.

Sandy is showing signs of possible physical and/or sexual abuse

You work with a nice, young mother going through a hard time. You think she might have substance abuse issues. She has 4 children. You work with the oldest boy who is seven. She has a new boyfriend and asked you to do respite and babysit for all of the kids so they can go out. You felt bad for the mother and agreed to it. It is now 11 am on the following day and there is no food for the kids. The mother was supposed be at home by 11 the night before and she is not answering her cell phone. You can't get a hold of anyone at your agency.

This is an example of programmatic abuse and neglect.

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Mary A. Steinberg, M.D. and Judith R. Hylton

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PRINCIPLES OF CAREGIVING DEVELOPMENTAL DISABILITIES MODULE

CHAPTER 6: INCIDENT REPORTING

FACILITATOR GUIDE

CONTENT:

- A. Types of Incidents
- B. Incident Reporting
 - 1. Basics: The purpose of incident reporting
 - 2. Steps to take when an incident occurs
 - 3. Reporting emergency measures
 - 4. When completing an incident report

Estimated time for this chapter: 1.5 hours

Needed Materials:

- 1. Facilitator Guide
- 2. Participant Guide
- 3. Incident Report Form (DD-191 FF 5-10)

COMPETENCIES:

(TO KNOW OR BE ABLE TO:)

1. Identify examples of incidents that need to be reported.
2. List the steps a DCW must take when an incident occurs.
3. List who needs to be notified about an incident.
4. Identify time frames for reporting incidents.
5. Identify essential components for documentation of an incident report.

KEY TERMS:

Emergency measure

Serious incident

Incident

Verbal report

Incident report

Written objectively

A. TYPES OF INCIDENTS

An incident is an event or occurrence that could potentially impact the health and well-being of an individual, his/her relatives, the State of Arizona, the service provider or the community. This could include situations that may be considered news-worthy and/or incur liability to the State of Arizona or the provider agency. An incident is **anything** that could negatively impact the person, the provider or the Division. **Incidents must be reported.**

Some incidents are considered “serious” incidents and have a higher reporting priority. If you are ever not sure if something would be considered a Serious Incident, just notify your supervisor right away and they will help you determine the reporting procedure that should be followed.

Facilitator Note:

Ask the group to call out things that they think could be considered an incident or serious incident based on the discussion so far. Provide positive reinforcement for all responses. Finish up by saying our slogan is: “If in doubt, fill it out!”

DISCUSSION POINT: What is an incident?

Facilitator Note:

State that there are times when we are required to complete a report; reporting is discussed in the second part of this chapter. Review the two lists below as needed to cover items that did not come up in the previous discussion.

Also refer to information on reporting in the Fundamentals portion of the course: chapter 2 - Legal and Ethical Issues (mandatory reporting, HIPAA); chapter 6 - Observing, Documenting, Reporting, and chapter 9 - Fire, Safety and Emergency Procedures.

Types of Incidents - Examples

Incidents can include, but are not limited to:

- Death of an individual.
- Potentially dangerous situations due to neglect of an individual.

- Allegations of suspected sexual, physical, programmatic, or verbal/emotional abuse.
- A missing individual.
- Accidental injuries that may or may not result in medical intervention.
- Violation of an individual’s rights.
- Fraud (for example: falsifying timesheets).
- Complaints about a group home or someone who live in a group home.
- Allegations of inappropriate sexual behavior.
- Circumstances that pose a threat to the health, safety or welfare of individuals, such as loss of air conditioning, loss of water or loss of electricity.
- Use of behavior management techniques that are not part of a behavior building plan.
- Theft or loss of an individual’s money or property.
- The use of emergency measures as defined by Article 9.
 - Physical management techniques employed in an emergency to manage a sudden, intense, or out-of-control.
- Problems with medications.
- Community disturbances in which the individual or the public may have been placed at risk.
- Serious work related illness or injury.
- Threats to Division or provider employees or property and non-consumer/non-employee accidents that occur on state or provider property.
- Unplanned hospitalization or emergency room visit in response to an illness, injury, or medication error.
- Unusual weather conditions or other disasters resulting in an emergency change of operations.
- Provider drug use.

Serious incidents

Serious incidents require immediate notification to the Division of Developmental Disabilities (DDD). The Division interprets “immediately” as the first allowable opportunity that does not place the consumer or staff at undue risk, as applicable to the situation. Notification must occur within 24 hours of the incident. If someone in your agency is not available, you are required to report this incident directly to the Division/support coordinator; check your agency’s policy for reporting. The DCW must also report all suspected incidents of abuse and neglect to the appropriate protective services and law enforcement agency.

Serious incidents could include, but are not limited to:

- All deaths.
- All suspected allegations of abuse and neglect.
- Any situation that poses a serious and immediate threat to the physical or emotional well-being of an individual or staff member.
- Severe personal injury – a physical injury that creates a reasonable risk of death, causes serious or permanent disfigurement or causes serious impairment of a consumer’s health.
- A situation in which a person, who cannot be unsupervised at home or in the community, runs away or is missing.
- Property damage estimated in excess of \$10,000.
- A situation that involves the theft or loss of an individual’s money or property of more than \$1000.
- A situation that involves reporting to law enforcement officials because a Division-enrolled individual is missing and presumed to be in imminent danger.
- A situation that involves reporting to law enforcement officials due to possession and/or illegal substance use by individuals or staff/providers.
- A situation that results in a 911 call due to a suicide attempt by an individual.
- A situation that involves an incident or complaint from the community that will be or is reported on the front pages of the newspaper or on television/radio.

Your employer may also want you to report damage to any property or other situations that are “out of the ordinary.” Your agency will determine whether to classify these incidents as serious or not.

Facilitator Note:

Discuss the idea that the difference between an incident and a serious incident is the severity of the incident. Incidents are typically less severe than serious incidents and involve a lower priority. Emergency measure reports are most similar to serious incidents, but include some additional reporting requirements.

B. INCIDENT REPORTING

1. Basics: The purpose of incident reporting

Facilitator Notes:

Ask the participants to discuss very quickly with the person next to them why incident reporting is important. After giving them a short amount of time to talk about it, ask the participants to

call out reasons why incident reporting may be important for the person that they are supporting. You may want to write their responses on a white-board or newsprint pad. Then repeat the process asking about why incident reports might be important for them as employees or contractors, their employer, the State of Arizona, etc. Once the answers become repetitive or the main topic areas have been covered, emphasize that incident reports have value in many different ways, primarily as the following.

- A communication tool.
- A way to protect the Direct Care Worker.
 - An incident report protects the direct care worker, the agency they work for, and the state of Arizona by ensuring that all responses to an incident are documented.
- A way to promote health and safety.
 - An incident report ensures that issues are addressed that could negatively affect the person.
- A method for gathering trending data.
 - Incident reporting helps the family and team to see patterns and provides a record of incidents and occurrences. This may benefit the family and team in addressing triggers or patterns of problems that have occurred.
- A way to reduce the likelihood of recurrence.
 - It allows the family and team to address problem areas. For example, if a person is hitting their shins as they get out of bed, causing injury and pain, an incident report will let everyone know that there is a problem with the bed or bedroom set up so that it can be changed.
- A way to provide communication between responsible parties, the Division of Developmental Disabilities, the provider agency, and the Direct Care Worker.
- A tool to report on issues of concern that need follow-up.
 - Without an incident report, the people who are in a position to make a difference may not know all the information they need to take action. The incident report allows the provider agency, that State of Arizona, and the responsible person and family (when appropriate) to take the steps needed to resolve a problem or issue.

HANDOUT:

Give each of the participants a copy of an incident report form - DD-191 FF (5-10). Review each of the components of the incident report form to ensure that the class participants are familiar with the layout and content of the form.

ACTIVITY:

- Have the participants work in pairs up or small groups.
- Hand out a sample scenario to each group.
 - Sample Scenarios can be found in the “Resources” section in the back of this Facilitator Guide.
 - You do not need to use every scenario. Choose the one(s) that you feel will be the most beneficial and meaningful for this particular class.
- Have the groups discuss the type of report (if any) that each scenario requires.
- Have the groups share their scenario, the type of report they identified for that scenario, and why they chose that type of report.

2. Steps to take when an incident occurs

“When in doubt, fill it out.”

In the event of a situation that could be considered an incident, follow these steps:

- First and foremost, take whatever actions are necessary to resolve any emergencies and ensure the health and safety of any individuals involved. This may include calling 911 or taking other emergency actions.

For incidents:

- Complete a written report of the incident as soon as possible, but before the end of your work day.
- The provider agency must provide the written report to the District (DES/DDD) by the close of the next business day. You, the Direct Care Worker, may be responsible for sending it, or your supervisor may ask you to give it to them and they will send it.
- A copy of the report must also be sent to the responsible person if there is one. Again, you may be responsible for sending it, or your supervisor may ask for the incident report to send it.

For serious incidents

- Complete a written report of the serious incident as soon as possible, but before the end of your work day.
- The provider agency must provide a verbal and written report to the Division.
- **Within 24 hours** of a serious incident the following actions must be taken:
 - The service provider must make a verbal report of the incident to the District (DES/DDD). There are after-hours reporting systems if the incident occurs after hours or on weekends.
 - A written report must be completed and submitted to the District (DES/DDD) within 24 hours of the incident.
 - Notification to the responsible person (guardian, family member, etc.) must be made within 24 hours.

Facilitator Note: The responsible person may be a guardian or family member. The responsible person must be notified unless it has been otherwise specified in the Individual Support Plan (ISP). Agency administrators may make this notification, or it may be made by the DES/DDD Support Coordinator. Occasionally, the direct support provide, may be asked to make the notification.

3. Reporting emergency measures

When an emergency physical management technique is employed to manage a sudden, intense and out-of-control behavior, the person employing the measure must:

- Immediately report the circumstances of the emergency measure to DES/DDD and the responsible person.
- After calling the above individuals, submit a full and complete written report of the circumstances of the emergency measure within one working day to the Support Coordinator and the District Central Reporting Site.
- The DCW responsibility in this is to ensure the immediate notification occurs and to write the Incident Report as quickly as is safe and prudent to do so, but before the end of their shift.

DES/DDD interprets “immediately” as the first allowable opportunity that does not place the client or staff at undue risk, as applicable to the situation, and not to exceed 24 hours.

In your report of an emergency measure you will want to include the following information:

- All interventions used before the emergency measure was implemented.
- A statement of how the individual’s behavior presented imminent danger (injury to self, others or severe property damage).

- That the behavior showed continuance, or a likelihood of continuing (the intensity was going to continue if you did not intervene).
- Information regarding any injuries that may have occurred and care steps taken to care for those injuries.

Facilitator Notes:

Stress the following information: These reporting requirements apply regardless of the time of day, or day of the week, when the incident report occurs. After-hours reporting systems are in place for incidents that occur after hours or on the weekends.

NOTE: As this process will vary from district-to-district, you, as the facilitator, must be knowledgeable about the process for the district in which you are teaching, and in which the direct care worker will be employed.

Emergency measures must be used according to the guidelines set forth in Article 9. You, as the facilitator, must be very familiar with these guidelines to ensure that you can answer any questions that may come up. Some emergency measure information is included in the resource section on of this facilitator guide.

4. When completing an incident report

All incident reports must be:

- Completed in blue or black ink. Your agency may require you to use a specific color.
- Corrected accurately.
 - If you make an error, draw a single line through the error and your initials and the date the change was made.
 - Never scribble out an error.
 - Never use correction fluid or tape on an incident report form.
 - Never erase anything on an incident report.
- Written clearly, objectively and in the order of occurrence, without reference to the writer’s opinion. Keep in mind that these reports are available to family/guardians and are considered legal documents. “Objective” means you state facts, not opinions.

Facilitator Note: Stress that when writing objectively, the author should state only the facts that they know. They should not include opinion.

A good example:

Music was playing on the radio in the living room. Sally came out of her room and made the statement “the music is bothering me. Please turn it off.”

Do not write:

Sally came storming out of her room because she didn't like the song that was playing on the radio and demanded that I turn it off. She was really mad.

All incident reports:

- Include demographic information like:
 - Full name
 - Address
 - Date of birth
 - Identification number

- Include the names and titles of all Direct Care Workers who witnessed the incident or were involved in it.

- Include a description of the incident including all known facts, location, and the date and time the incident occurred.

- Include causes of injury (if applicable).

- State whether or not the responsible person was notified and, if not, the reason.

- Include whether or not law enforcement, Adult/Child Protective Services, or Tribal Social Services have been contacted.

- Include signatures and names of the person completing the report and his/her supervisor and any additional comments.

- Must be completed for each individual involved in the incident and not breach the confidentiality of other individuals.

- Must be maintained by the provider agency and the Division of Developmental Disabilities Support Coordinator.

If more than one individual who receives services through the Division of Developmental Disabilities is involved in the incident, write a separate report for each person. Use only the individual's name for which the report is being written. Refer to other persons generically, e.g. housemate, roommate, peer, friend, etc.

ACTIVITY:

To help ensure content mastery and provide an opportunity to practice have the participants complete the activity listed below.

- Break the class into pairs or small groups.
- Provide a different sample incident to each group. There are sample scenarios in the resource section of this Facilitator’s Guide.
- Have the participants work as pairs or small groups to write an incident report based on the information provided.
- Discuss the type of report they identified and facilitate a discussion about the type of reports each group identified and the criteria that made it fit in the identified category.
- Have the groups exchange reports.
- Set up the next step by reminding the groups that this is a learning activity and to stay constructive and positive with their feedback.
- Have the groups provide written feedback in the “CORRECTIVE ACTION/COMMENTS” section of the incident report focusing on the three things that could make the report more clear and the three best things about the report. Emphasize that the feedback should be positive and constructive.
- Have the groups continue to exchange reports until each group has their original report back. Remind the groups that the feedback is designed to help them learn and that they should take the useful parts of the feedback and use it to make future reports better. If they disagree with any of the feedback, that’s fine.
- Ask the groups if they have any questions or need any clarification on the report they completed or other issues that may have come up during the exercise.

Note:

It is a good idea to provide one or more written examples of incident reports for participants to view as handouts.

Facilitator Notes:

Utilizing the activity listed below, have participants practice distinguishing between an Incident Report and a Serious Incident Report and the reporting steps for each.

ACTIVITY:

- Have the pairs or small groups use the reports that they just created with their partners or small groups, or if there is adequate time, assign them a new scenario and have them write a second Incident Report / Serious Incident Report / Emergency Measure Report.
- Add the step of identifying the reporting procedures required for each type of report.
- Have the groups document on the incident report next steps the DCW should take in response to the incident.

Facilitator Notes:

Summary: Provide a brief review of the course content and ask if anyone has questions before wrapping up.

- Be sure to emphasize the importance of incident reports in regard to:
 - Effective communication.
 - Preventing incidents from happening again or identify new risks to the person.
 - Maintaining accurate records.
 - Legal protection.
- Briefly reiterate the 3 types of reports (Incident Reports, Serious Incidents, and Emergency Measure Reports) and the reporting criteria for each.
- Briefly reiterate the timelines for reporting.
- Answer any additional questions that the participants may ask.

FACILITATOR RESOURCES

PRACTICE SCENARIOS

Instructions:

1. Using a blank incident report form, complete a practice report based on the scenario you have been assigned.
2. You may not have all the information you need to complete the report. Dates and times are not provided. You should use the current date and time. The incident you have been assigned may ask you to create other information. Unless otherwise stated, only report what you know.
3. Remember your incident reporting basics:
 - a. Use ink only.
 - b. Use proper correction: ~~error~~^{mn}
 - c. Maintain confidentiality.
 - d. State only facts.
 - e. Cite your sources.
 - f. Use quotes when possible.
 - g. Be clear – use bullet points for clarity.
4. Be sure to complete all the blanks (including notifications).
5. Relax... this is not a test. It is practice. Feel free to use your packet and your classmates.

Incident Reporting - Practice Scenario 1

Name: Sally Sample

Address: 1234 Elm Street Townplace, Arizona 85000

Phone: 480-555-5555

Assists ID #: 1234567

Birth date: 6/11/1988

Provider: ACME PROVIDERS

Parent: Sandra Sample

Support Coordinator: Ima Good

Sally falls down getting out of the vehicle at home. She scrapes her knee. You clean the wound and provide first aid. Sally reports that her knee is feeling better. She appears to be walking normally, and is fully participating in all activities.

Incident Reporting - Practice Scenario 2

Name: Sally Sample

Address: 1234 Elm Street Townplace, Arizona 85000

Phone: 480-555-5555

Assists ID # 1234567

Birth date: 6/11/1988

Provider: ACME PROVIDERS

Parent: Sandra Sample

Support Coordinator: Ima Good

Sally has a home-theater set-up stolen from her room. The set-up included a plasma TV, stereo equipment, speakers, etc. valued at \$3500.00

Incident Reporting - Practice Scenario 3

Name: Sally Sample

Address: 1234 Elm Street Townplace, Arizona 85000

Phone: 480-555-5555

Assists ID #: 1234567

Birth date: 6/11/1988

Provider: ACME PROVIDERS

Parent: Sandra Sample

Support Coordinator: Ima Good

While at a local restaurant, you are approached by an angry (apparently intoxicated) person from the community. He states that he does not want to eat in the same restaurant as “those people” and points at Sally and her roommate Maya. The management asks him to leave. When he refuses, they call the police. The police arrive within minutes and escort the man out of the restaurant.

Incident Reporting - Practice Scenario 4

Name: Sally Sample

Address: 1234 Elm Street Townplace, Arizona 85000

Phone: 480-555-5555

Assists ID #: 1234567

Birth date: 6/11/1988

Provider: ACME PROVIDERS

Parent: Sandra Sample

Support Coordinator: Ima Good

An individual from the community enters the restaurant where you are having lunch with Sally. They begin to make “inappropriate” and insulting comments to Sally. When the restaurant manager asks them to leave, they begin screaming and cussing but agree to leave. They tip over a chair on the way out.

Incident Reporting - Practice Scenario 5

Name: Sally Sample

Address: 1234 Elm Street Townplace, Arizona 85000

Phone: 480-555-5555

Assists ID #: 1234567

Birth date: 6/11/1988

Provider: ACME PROVIDERS

Parent: Sandra Sample

Support Coordinator: Ima Good

While preparing for dinner, you knock several plates off the table breaking them. No one receiving support is involved.

Incident Reporting - Practice Scenario 6

Name: Sally Sample

Address: 1234 Elm Street Townplace, Arizona 85000

Phone: 480-555-5555

Assists ID #: 1234567

Birth date: 6/11/1988

Provider: ACME PROVIDERS

Parent: Sandra Sample

Support Coordinator: Ima Good

When completing a routine “bed check” at 2:00 am you notice that Sally is missing. You contact the police and your supervisor. She has not been located as of the end of your shift.

Incident Reporting - Practice Scenario 7

Name: Sally Sample

Address: 1234 Elm Street Townplace, Arizona 85000

Phone: 480-555-5555

Assists ID #: 1234567

Birth date: 6/11/1988

Provider: ACME PROVIDERS

Parent: Sandra Sample

Support Coordinator: Ima Good

While providing paid support to your niece, Sally, you observe her mother call her an idiot and slap her repeatedly.

The mother stops when you intervene, and then explains that she was just frustrated with Sally. She states that she “can’t believe she lost control like that” and promises that it will never happen again.

Incident Reporting - Practice Scenario 8

Name: Sally Sample

Address: 1234 Elm Street Townplace, Arizona 85000

Phone: 480-555-5555

Assists ID #: 1234567

Birth date: 6/11/1988

Provider: ACME PROVIDERS

Parent: Sandra Sample

Support Coordinator: Ima Good

After taking her medication Sally realizes that she just took 1000mg of Tegretol instead of the 500mg that she has been prescribed. You contact the prescribing physician and are told to monitor her for side effects.

Incident Reporting - Practice Scenario 9

Name: Sally Sample

Address: 1234 Elm Street Townplace, Arizona 85000

Phone: 480-555-5555

Assists ID #: 1234567

Birth date: 6/11/1988

Provider: ACME PROVIDERS

Parent: Sandra Sample

Support Coordinator: Ima Good

Sally reports to you that a staff member named Jim Doe hit her yesterday while she was at her day program.

Incident Reporting - Practice Scenario 10

Name: Sally Sample

Address: 1234 Elm Street Townplace, Arizona 85000

Phone: 480-555-5555

Assists ID #: 1234567

Birth date: 6/11/1988

Provider: ACME PROVIDERS

Parent: Sandra Sample

Support Coordinator: Ima Good

Sally suddenly becomes unconscious. You call 911. The paramedics transport her to the hospital.

Incident Reporting - Practice Scenario 11

Name: Sally Sample

Address: 1234 Elm Street Townplace, Arizona 85000

Phone: 480-555-5555

Assists ID #: 1234567

Birth date: 6/11/1988

Provider: ACME PROVIDERS

Parent: Sandra Sample

Support Coordinator: Ima Good

A reporter from a local newspaper approaches you and begins questioning you about the job you do, the individuals that you work with and your relationship with the State of Arizona.

Incident Reporting - Practice Scenario 12

Name: Sally Sample

Address: 1234 Elm Street Townplace, Arizona 85000

Phone: 480-555-5555

Assists ID #: 1234567

Birth date: 6/11/1988

Provider: ACME PROVIDERS

Parent: Sandra Sample

Support Coordinator: Ima Good

During a monsoon storm, lightning strikes a large tree in the back yard, catching it on fire. You call the fire department. They arrive a few minutes later and put out the fire within minutes.

Incident Reporting - Practice Scenario 13

Name: Sally Sample

Address: 1234 Elm Street Townplace, Arizona 85000

Phone: 480-555-5555

Assists ID #: 1234567

Birth date: 6/11/1988

Provider: ACME PROVIDERS

Parent: Sandra Sample

Support Coordinator: Ima Good

Sally experienced a seizure. During the seizure she hit her head on the ground causing swelling and bleeding. You call 911 and she is transported to the hospital where she is kept overnight for monitoring.

Incident Reporting - Practice Scenario 14

Name: Sally Sample

Address: 1234 Elm Street Townplace, Arizona 85000

Phone: 480-555-5555

Assists ID #: 1234567

Birth date: 6/11/1988

Provider: ACME PROVIDERS

Parent: Sandra Sample

Support Coordinator: Ima Good

While at a local park, Sally grabs a small child and shakes it. The child was frightened, but not injured. You spoke briefly with the child's angry mother and gave her your supervisor's contact information.

Incident Reporting Practice Scenario 15

Name: Sally Sample

Address: 1234 Elm Street Townplace, Arizona 85000

Phone: 480-555-5555

Assists ID #: 1234567

Birth date: 6/11/1988

Provider: ACME PROVIDERS

Parent: Sandra Sample

Support Coordinator: Ima Good

Sally is stopped by the police and found to be in possession of marijuana. She contacts you from jail. You notify your supervisor.

Incident Reporting - Practice Scenario 16

Name: Sally Sample

Address: 1234 Elm Street Townplace, Arizona 85000

Phone: 480-555-5555

Assists ID #: 1234567

Birth date: 6/11/1988

Provider: ACME PROVIDERS

Parent: Sandra Sample

Support Coordinator: Ima Good

When you attempt to wake Sally up in the morning, you discover that she died during the night.

Emergency Measure Resource Information

**From the Article 9 standardized curriculum
Adopted and approved 12/9/2002 and revised 9/09, page 23**

REPORTING EMERGENCY MEASURES

1. Emergency Measures:

Definition of an “Emergency Measure”: In the event that an individual engages in a sudden, intense, out of control behavior endangering the health or safety of the individual or another person, the use of physical management techniques and/or behavior modifying medication with a physician’s order for specific one time emergency use.

Note: Emergency measures described here are not to be confused with the prohibited technique of physical restraints, including mechanical restraints, when used as a negative consequence to a behavior as listed in R6-6-902.A.4.

The team must meet and consider writing a behavior plan when an emergency measure is used two or more times in a 30 day period or any identifiable pattern.

2. Emergency Physical Management Techniques:

When the behavior plan techniques are ineffective, staff shall use the least amount of intervention necessary to safely physically manage the individual’s out-of-control behavior. These techniques are included in Client Intervention Training (CIT) and shall be:

- used only by individuals specifically trained in the use of Client Intervention Techniques
- used only when less restrictive methods were unsuccessful or inappropriate
- used to prevent the individual from harming him or herself or others or causing severe damage to property
- continued for the least amount of time necessary to bring the individual’s behavior under control
- be used concurrently with the uncontrolled behavior
- be appropriate to the situation to insure safety

3. Reporting Procedures:

When a physical management technique is employed to manage a sudden, intense behavior, the person employing that measure shall:

Chapter 6: Incident Reporting – If in doubt, fill it out!

- a. Immediately (*The Division interprets “immediately”, as the first allowable opportunity that does not place the individual or staff at undue risk, as applicable to the situation, and not to exceed 24 hours*) report the circumstances of the emergency measure to the following:
 1. The person designated by the Division
 2. The responsible person
- b. After calling the above individuals, a full and complete written report of the circumstances of the emergency measures needs to be submitted within one working day to the support coordinator and the district central reporting site.

PRINCIPLES OF CAREGIVING DEVELOPMENTAL DISABILITIES MODULE

CHAPTER 7: DAILY LIVING

FACILITATOR GUIDE

CONTENT:

- A. Introduction
- B. Meal Assistance
 - 1. Assistance with setting up a meal
 - 2. Assistance with eating
 - 3. Feeding an individual who has difficulty swallowing
 - 4. Feeding an individual with a cognitive disability
 - 5. Risk factors for choking
 - 6. Encouraging appetite
 - 7. Assistive devices for eating
- C. Assistance with Medication Self-Administration
- D. Skin Integrity
- E. Bathing, Dressing, and Grooming
 - 1. Skin care
 - 2. Bathing
 - 3. Hair care
 - 4. Dressing
 - 5. Shaving
 - 6. Nail care
 - 7. Assistive devices
- F. Oral Hygiene
- G. Toileting
- H. Transferring
 - 1. Principles of body mechanics for back safety
 - 2. Use of the gait belt
 - 3. Transfer out of bed
 - 4. Transfer from wheelchair
 - 5. Ambulation (walking)
- I. Turning and positioning
 - 1. Preventing pressure sores
 - 2. Preventing contractures
 - 3. Range of motion (ROM) exercises
 - 4. Assistive devices

Estimated time for this chapter: 3 hours (varies with number of participants)

Needed Materials:

1. Facilitator Guide
2. Participant Guide
3. Equipment: wheelchair, gait belt, walker, bed and bedding, clothing, food items, plate, cup, flatware, toothbrush / toothette, toothpaste

**COMPETENCIES:
(TO KNOW OR BE ABLE TO:)**

1. Give examples of techniques that can be used to promote independence and respect a person's preferences (for example, at mealtimes).
2. Identify resources to identify an individual's mealtime needs.
3. Identify characteristics of people at risk for choking.
4. Identify choking prevention measures a DCW can use during mealtime.
5. Give examples of techniques that can be used to preserve dignity and privacy while providing personal care.
6. List risk factors for skin breakdown.
7. Explain the importance of repositioning and list techniques for preventing skin damage and pressure ulcers.
8. Identify and describe common assistive devices, including gait belt, walkers and wheelchairs.
9. Explain the importance of proper transfer skills and the safe use of assistive devices.
10. Identify issues related to providing assistance with bathing and using the bathroom.
11. Describe and role-play techniques for positioning and transferring a person.
 - a. Use of gait belt.
 - b. Assistance with ambulation (with/without assistive devices).
 - c. Techniques for positioning a person in bed.
 - d. Techniques for positioning a person in a wheelchair.
 - e. Transfer in and out of a wheelchair (with or without assistive devices).
 - f. Transfer out of bed (sofa).
12. Simulate/role-play or describe assistance with ADLs.
 - a. Assistance with dressing.
 - b. Assistance with meals (total assistance/feeding, and prompting, hand-over-hand assistance).
 - c. Assistance with brushing teeth.

KEY TERMS:

Activities of daily living (ADL)	Incontinence
Ambulation	Pressure sore (ulcer)
Assistive device	Range of motion exercises
Choking	Skin integrity
Contracture	Transfer, transferring
Gait belt	Walker
Grab bar	Wheelchair

A. INTRODUCTION

Facilitator Note:

Activities of daily living skills (ADL) are functional skills required for a person to live independently. Supporting a person with ADLs is a key component of a DCWs responsibility. In this section we will discuss ways to provide assistance that promotes self respect, self determination and as much independence as possible.

1. Activities of Daily Living (ADLs)

ADLs are considered a person's basic, self-care tasks. They include the ability to:

- a. Dress
- b. Eat
- c. Walk and transfer
- d. Use the restroom (toilet)
- e. Take care of hygiene needs (e.g., bathing, grooming)

In addition, there are the Instrumental Activities of Daily Living (IADLs). These activities are important for the individual to function in the community:

- a. Shop
- b. Keep house (clean, do laundry)
- c. Manage personal finances
- d. Prepare food
- e. Transport (e.g., driving)

This chapter focuses on the **personal care needs (the ADLs)** and how to provide assistance to meet those needs. Assistance with some of the IADLs (housekeeping, food preparation) is addressed in the Fundamentals course book.

2. Following Support Plans

The planning process will identify individualized supports that are important in assisting the person to obtain his or her goals. Supports can include assistance with personal needs, or activities of daily living. The support plan describes the person's abilities and needs.

Facilitator Note:

Supports provided through Home and Community Based Services (HCBS) may include:

- Respite: Supervise and care for an individual in order to relieve the primary caregivers.
- Attendant Care: Assist a person to attain or maintain safe and sanitary living conditions and/or maintain personal cleanliness and activities of daily living. An attendant care agreement is created specific for each individual, outlining the DCW's tasks.
- Habilitation: Teach and assist a person in learning a skill.

Components of the support plan that help identify areas of assistance include:

- The Action Plan section identifies areas and skills the individual and planning team have identified that will assist with skills acquisition to move the person towards independence. This is where the team documents specific teaching plans or outcomes. Division-funded outcomes or behavior building plan outcomes must be listed here. Additionally, this may include academic goals, self-help goals, or other goals the individual/family have identified to work on privately or with other agencies.

The DCW is responsible for the implementation of the support plan in their area of support. This includes supporting a person with ADL needs. The DCW must follow the agreed upon support plan. If the individual or family wants you to do something that is not in the support plan, you may be opening yourself and the agency to disciplinary and/or liability issues. Contact your supervisor if such a situation arises. (Refer to chapter4 - Support Plans).

3. How much assistance is enough?

When supporting ANY individual, regardless of condition, whether a family member or a consumer, the DCW should remember to support the person to remain as independent as possible. Consumers should be encouraged to do as much as they can for themselves. The DCW can find out how much assistance is needed by:

- a. Reviewing the support plan for instructions. Check to see if the person is independent or needs minimum or total assistance for tasks.
- b. Asking the consumer/family to determine what they can do. Assist but don't take over the task.
- c. Observing what the person can do and what he/she can learn.
- d. Continuing to communicate with the consumer and family – needs and abilities may change, sometimes daily.

Facilitator Note:

Standardized Testing

- Can be used in evaluating an individual's capacity for self-care and his or her ability to function independently in the context of everyday living.

Interviews

- Speak directly with the person about those daily living skills and community living skills that are the most important for living for the individual's living situation.
- Interview parent(s) for input of those daily living skills and community living skills they feel are most important for the person receive assistance.

File Review

- Documentation from previous assessments conducted by other support providers.
- Any previous medical assessments or documentation.
- Any previous educational assessments or documentations.

Conduct formal or informal observations

- Observe the person performing daily living activities.
- Simulated task observation is an alternative if you are unable to witness actual ADL skills being performed, e.g., meal preparation, grooming, etc.

Therapist evaluations (OT, PT, etc.)

- Review therapy evaluations and assessments.
- Talk with therapist about ways to assist the person with ADLs.

Optional Activity:

- Have participants break up in groups.
- Have each group identify five key words that would describe a caregiver.
- Have each group identify five key words that would describe a direct support professional.
- Have each group take a list of skills:
 - Tooth Brushing
 - Dressing
 - Bathing
 - Eating
- Have each group identify how they would approach each skill differently based on the approach as a caregiver compared to an approach as a direct support professional.

In summary, your role as a direct support person is to promote and encourage as much independence and personal growth. We do not want people we support to become more reliant on others. We want to build self-esteem, self-determination and purpose in life.

B. MEAL ASSISTANCE

Direct Care Workers may help individuals at mealtimes. Whenever possible, the individual should eat with a minimum of assistance. If needed, adaptive equipment should be available to the person to encourage self-feeding. Feed a person only if he/she is unable to do so.

1. Assisting with setting up a meal

- The individual should be sitting with his/her head elevated to prevent choking.
- Cut meat, open cartons, butter bread if assistance is needed.
- Use clock description for a person with a vision impairment (e.g., meat is at 12:00; salad is at 4:00, etc.).

2. Assistance with eating

Providing assistance with eating and/or feeding a consumer is a skill that many Direct Care Workers will use on a daily basis. The purpose of this skill is to ensure that the DCW knows the correct technique for assisting with and/or feeding another individual.



Procedure: Assisting with Eating:

Supplies

- Spoon and/or fork, napkin, bowl or plate, clothing protector, cup.
- Food items.

Description of Procedure

1. Maintain dignity and safety of at all times.
2. Check support plan (risk assessment) or with supervisor to determine if choking hazard exists and to verify the consistency of food required. Check if any foods are prohibited due to allergy or choking hazard.
3. Ensure that you cut up meat, open cartons, butter bread, etc. if that type of assistance is needed.
4. Sit next to the individual at eye level.
5. Ensure that the individual is sitting with his/her head elevated to prevent choking.
6. Provide ONLY the amount of assistance that is necessary (graduated guidance, hand over hand, etc). **Encourage the person to be as independent as possible.**



7. Check the temperature of food before you begin. Feel the container, observing for steam, to ensure the food is at an acceptable temperature.
8. Explain what foods are on the plate. For someone with a visual impairment, use the clock description method (i.e., "Your meat is at 12:00, vegetables are at 3:00," etc.).
9. Ask the individual what he/she wants to eat first.
10. Watch the individual to make sure food is swallowed before giving additional food or fluids. Remind the individual to chew and swallow as necessary.
11. Offer liquids at regular intervals.
12. Engage the person in pleasant conversation while completing this task, but don't ask questions that take too long to answer.
13. Do not rush the individual.
14. Once the meal is complete, ensure that you help the individual in wiping his/her face and washing hands as necessary.

Practical Tips:

- Be aware of how the individual may be feeling in regards to needing assistance. Allow the person to make their own food choices; give options and respect preferences.
- Be aware of any issues causing the individual to tire or get frustrated easily.
- Pay special attention to individuals who may present a choking hazard.
- Ensure that you are communicating with the individual about the pace in which you are feeding or assisting him/her with eating.

Don't forget!

- Don't do everything for the person just because it is faster for you. Only provide the assistance that is truly needed.
- Don't assume the individual likes every item that has been served.
- Don't treat the person like a child. For example, do not wipe person's mouth with the spoon.
- Serve food in proper consistency to avoid choking.

3. Feeding a person who has difficulty swallowing (Dysphagia)

- Position the person upright in a chair to prevent choking or aspiration (inhaling liquids).
- Keep the person oriented and focused on eating.

- Help him/her control chewing and swallowing by choosing the right foods (a diet containing food with thick consistency, which is easier to swallow) such as:
 - o Soft-cooked eggs, mashed potatoes and creamed cereals
 - o Thickened liquids are often used.
- A variety of textures and temperatures of foods stimulate swallowing; vary foods offered from the plate.
- At times dysphagia is temporary. A person who is temporarily ill may have difficulty swallowing, which improves after recovery from illness.

4. Feeding an individual who has a cognitive disability

- Avoid changes. Seat the person at the same place for all meals.
- Avoid excessive stimulation. Too much activity and noise often adds to confusion and anxiety. Remove distractions, if possible, and gently refocus the person.
- Meals should be ready to eat when the person is seated (e.g., meat is cut, bread is buttered, etc.).
- Avoid isolating the person. Isolation leads to more confusion.
- Call a person by a name he/she prefers. Achieve and maintain eye contact.
- Use a calm voice; speak softly, slowly, clearly and face the person.
- Keep communication simple. Use simple, short instructions such as “pick up your fork,” “put food on your fork,” “put the fork in your mouth.”
- Use objects or hand movements to help with cueing.

5. Risk factors for choking

Choking is a blockage of the upper airway by food or an object that prevents someone from breathing. It is a medical emergency that requires fast action. This includes an immediate call to 911, followed by efforts to dislodge the object that is causing the choking. Choking is a major cause of medical injuries, but it can be prevented.

Direct Care Workers must review the individual support plan’s risk assessment document to identify risk factors related to mealtime and choking. They also must verify with the individual/family any mealtime instructions – **including choking risks.**

Why are individuals with developmental disabilities at risk of choking?

People with developmental disabilities share a number of common characteristics that place them at high risk for choking/aspirating, to include:

- Decreased or absent protective airway reflexes as occurs in cerebral palsy.

- Poor or underdeveloped oral motor skills that do not permit adequate chewing or swallowing.
- Gastroesophageal reflux disorder (GERD), which may cause aspiration of refluxed stomach contents.
- Seizures.
- Inability to swallow certain fluid consistencies and/or food textures.
- Medication side effects that decrease or relax voluntary muscles, causing delayed swallowing or suppression of the protective gag and cough reflexes.
- Impaired mobility, which may leave individuals unable to properly position themselves for adequate swallowing.

Signs of choking:

- Inability to talk.
- Wide-eyed panicked look on face.
- Difficulty breathing or noisy breathing.
- Inability to cough forcefully.
- Skin, lips, or nails turning blue or dusky.
- Loss of consciousness.

Food that commonly causes choking:

- Sandwiches, for example: peanut butter and jelly sandwiches.
- Meat: steak, hamburgers, hotdogs and chicken.
- Vegetables, particularly when they are uncooked.
- Fruit, particularly fruits with their skin on.
- Snack food: popcorn, nuts, hard candy, chewing gum, and raisins.
- Burritos.

Special Risks for People with Swallowing Disorders

People with swallowing disorders are at a higher risk of aspiration of food and liquids (breathing food into the lungs). Food that is difficult to chew or swallow because of its shape, size, or texture further increases the risk of aspiration or choking.

People with swallowing disorders should avoid the following types of food:

Hot dogs	Marshmallows	Hard Candy	Potato Chips
Tossed Salad	Meat Chunks	Raw Apple	Chewing Gum
Chicken on bone	Corn Chips	Pretzels	Nuts (all types)
Popcorn	Hard Beans	Thick Chewy Bread	Tortilla Chips
Bagels	Grapes	Raw Carrots	Caramel
Raisins	Canned Fruit	Celery	Rice

Common causes of choking

Eating and chewing:

- Eating or drinking too fast.
- Placing too much food in one's mouth.
- Not chewing food well enough prior to swallowing.
- Swallowing inedible objects.
- Teeth-related factors, for example:
 - o Having no teeth.
 - o Having only a few teeth or a tooth ache, which may cause someone to not chew his or her food properly.
 - o Dentures can make it difficult to sense whether food is fully chewed before it is swallowed.

- o If dentures fit poorly or hurt, individuals may not chew their food or may not wear the dentures at all.

Distractions:

- Inattention to eating.
- Laughing or talking while eating.
- Walking, playing or running with eating utensil or objects in mouth.
- Distractions by other persons or activities.
- Food stealing.

Diet:

- Incorrect diet texture - liquids or food items not prepared in accordance with prescribed diet.
- Eating something with two or more diet textures, especially anything with a thin liquid and a solid component, such as cereal and milk.

Staff assistance:

- Inadequate supervision.
- Inadequately trained staff.
- Not familiar with prescribed diet.
- Poorly assisted eating techniques.
- Poor positioning.

What to do if someone chokes:

Anyone unable to cough forcefully, speak or breathe may be choking.

Immediately call 911!

Reproduced with permission from the State of New Jersey, Department of Human Services, Division of Developmental Disabilities. You can get the complete Health and Safety Alert at: http://www.state.nj.us/humanservices/ddd/documents/Documents%20for%20Web/Health_SafetyAlert_choking_071509.pdf

6. Encouraging intake and appetite: appeal to all the senses

- Pay attention to the presentation of food. Set the table with tablecloth and/or placemats.
- Have a meal with a theme such as South of the Border or Italian.
- Keep the table conversation positive and pleasant (Never say, "If you don't eat, you won't get dessert.").
- Make sure eyeglasses are on and clean (increases visual appeal).
- May need to increase spices to make food more appealing.

7. Assistive devices

Encourage each person to eat as independently as possible. This supports a person's self sufficiency, self-esteem and can save time. Sometimes a person may need to be fed or "guided" through a meal. The following are general considerations:

- Provide adaptive devices, such as a rocker knife, which allows one-handed cutting.
- Provide foods that do not require use of utensils (e.g., "finger" foods, soup in a mug).
- Build up handles on utensils to make them easier to grasp.
- Use contrasting colors in place setting.
- Be consistent in placing food on a plate and on the table in specific order. For example, potatoes are at the 3:00 o'clock, meat is at 9:00 o'clock position, for visually impaired persons.

Facilitator Note: Optional Activities:

- Break the class up into small groups play a "game show" on assisting with meals.
 - o Each group has one representative respond to each question.
 - o The first person to respond with the correct answer earns a point for their team.
 - o The time with the most points wins the game.
- **Possible Questions**
 - o Identify 3 resources to that will provide information on an individual's mealtime needs.
 - o Identify four characteristics of people at risk for choking.
 - o Give examples of four techniques that can be used to promote independence and respect a person's preferences when assisting a person at mealtime.
 - o Give examples of three adaptive devices that can be used at mealtime to help a person maintain independence.

C. ASSISTANCE WITH MEDICATION SELF-ADMINISTRATION

A critical responsibility of a Direct Care Worker's job is ensuring the health and well-being of the individuals you support. In some cases, this includes ensuring that medications are taken correctly.

If you are ever unsure about any aspect of assisting a person to take his/her medication(s), stop, contact your supervisor or other person designated by your agency, and get clarification before you continue.

1. Definitions

Assistance means the help or aid necessary to complete a function or a task.

The Direct Care Worker may provide the assistance necessary for a person to take his/her medication.

Direct self-care means a person is able to recognize danger, summon assistance, express need, and make basic care decisions.

A person who is able to "direct self-care" can instruct the Direct Care Worker to assist by opening the medication bottle; placing the medication in his/her mouth and providing a drink of water.

Directed care services means programs and services, including personal care services, provided to persons who are incapable of recognizing danger, summoning assistance, expressing need or making basic care decisions.

When providing "directed care services," the Direct Care Worker may provide assistance by taking direction from the responsible person, including providing the help necessary for the person to take his/her medication.

Documentation means written supportive information.

The Direct Care Worker must keep documentation by recording the date and time of day when assistance with medication self-administration was provided.

2. Where to find information about providing assistance with medication self-administration

The person's Individual Support Plan (ISP) provides support information about medication(s) taken and the amount of assistance needed for medication self-administration. The ISP states whether the consumer needs assistance in the self-administration of medication and any special instructions about the type of assistance:

- a. Requires no assistance in the self-administration of medication or medication administration;
- b. Needs assistance in the self-administration of medication, which can include:
 - Reminding a consumer that it is time to take a medication;
 - Opening a medication container for a resident;
 - Pouring or placing a specified dosage as instructed by the consumer into the consumer's hand;
 - Observing the consumer while the medication is taken; or
 - Assisting the consumer to take the medications that have been prepared in advance in a medication organizer by the responsible person.
- c. Needs total assistance, which includes use of medication organizers.
 - Medication organizers may be prepared in advance by the responsible person. There need to be clear, simple instructions from the responsible person. Example: The medication needs to be in a container that is clearly marked, "Please give to my mother at 10 am with a glass of water." (Only the exact dose is in the container so that the DCW does not have to decide how many pills to use.)

3. What to document

Document that medications were administered according to the consumer's instructions or according to medication organizer date and time, as directed by the responsible person.

4. What you cannot do

- A DCW cannot use professional judgment and cannot make decisions about medications.

- If the consumer does not know which medication is which, the DCW cannot help figure this out.
- If the consumer is confused about dosage/time etc., the DCW cannot help sort it out.

D. SKIN INTEGRITY

Facilitator note:

Introduce this section by explaining the following:

Older adults and persons with disabilities are susceptible to skin problems because of decreased mobility. This can be due to medical conditions, pain, depression, confusion and/or injury. **Therefore, it is critical for a DCW to routinely check a person's skin for any changes and report any changes to his/her supervisor.** Early intervention is of utmost importance in maintaining skin integrity.

Any person who sits still for a long time may be at risk for skin problems. **It is critical for a DCW to routinely check a person's skin for any changes. Report any changes to your supervisor.**



Contact your supervisor before proceeding with any action related to skin problems.

Pressure Ulcers

Facilitator Note:

Pressure ulcers (also called pressure sores or decubitus ulcers) are lesions to the skin caused by unrelieved pressure resulting in damage to underlying tissue. Pressure compresses the skin tissue, causing decreased circulation. This can lead to decreased oxygen and nutrients and ultimately the death of the tissue.

Pressure ulcers are lesions to the skin. They are also called pressure sores or decubitus ulcers. Pressure on the skin compresses tissue and can lead to the death of the tissue.

Common problem sites are bony prominences:

- Tailbone.
- Heels.
- Elbows.

Common sources of pressure are:

- Sitting or lying in one position too long.
- Casts, braces, or crutches that rub.
- Wrinkled bed linens and poorly fitting clothes.
- Moisture and other skin irritants.

Facilitator Notes:

Other Contributing Factors

1. **Friction:** Friction occurs when a person's body rubs against a surface or an object rubs against the skin. For example, sliding a person can scrape or scratch dry, tender skin.
2. **Moisture:** Prolonged exposure to moisture from sweating and incontinence changes the protective nature of skin. Damp skin becomes swollen, soft and irritated, making it susceptible to sores, rashes, and fungal infections.
3. **Dehydration and poor diet:** Adequate fluid intake is essential to maintaining healthy skin. Water and foods rich in protein and vitamins (especially vitamin C and zinc) help the body resist trauma, fight infection and promote healing.
4. **Body weight:** Being overweight or underweight increases the risk of skin problems.
5. **Illness:** Diabetes, heart disease, and poor circulation increase the risk of pressure sores.
6. **Limited mobility and awareness:** Willingness and ability to engage in activities may be reduced by pain, sedation, low energy, or motor or mental deficits.
7. **Irritants:** Chemicals (including urine) and other substances (e.g., anti-bacterial soaps) can irritate and inflame the skin. Allergic reactions can produce rashes. A skin ulcer can form at the site of irritation.
8. **Injury:** The risk of skin breakdown increases at the site of an injury. A burn from a heating pad, a scratch, bruise, or scrape can develop into an ulcer if not properly treated.
9. **Smoking:** Persons who smoke have decreased circulation and heal more slowly.

What you need to look for and report:

- Red skin that stays red.
- Patches of hard skin, blisters, or abrasions.
- Open sores.

Facilitator Notes:

Stages of Skin Damage

Stage I: The skin is reddened and the color does not return to normal 20 minutes after the pressure is relieved. The skin remains intact. In individuals with darker skin, discoloration of the skin, warmth, edema (fluid accumulation), or a hardened area may be indicators.

Stage II: There is partial thickness skin damage, affecting the outermost skin layer (epidermis) and the layer below it (dermis), or both. The ulcer is superficial and looks like an abrasion or blister.

Stage III: This involves the full thickness of the skin, extending into the underlying tissues. This deeper layer of skin tissue has a relatively poor blood supply and can be difficult to heal. The

ulcer is a deep crater with or without undermining (tunneling) of adjacent tissue.

Stage IV: There is full thickness skin loss with extensive destruction, tissue dying (necrosis), or damage to muscle, bone, or supporting structures.

What you can do to prevent pressure ulcers:

- a. **Avoid prolonged exposure:** Remind or help the individual to change position at least every 2 hours. If an area stays reddened for more than 20 minutes, reduce time for changing position by 30 minutes.
 - The person should relieve pressure on the tailbone (from sitting or lying) every 20-30 minutes by pushing up with arms, shifting from side to side, or leaning forward, feet on the floor. Make sure the person does not fall.
 - Encourage mild exercise and activities that do not involve sitting for long periods of time.
 - Be sure bedding and clothing under pressure areas (tailbone, elbows, and heels) are clean, dry and free of wrinkles and any objects.
 - It is the DCW's responsibility to change the person's position at least every 2 hours if the person is unable to do so (for example, an individual who has quadriplegia).
- b. **Avoid skin scrapes from friction.** Consider the following to prevent these scrapes:
 - Follow safe transfer procedures. Do not drag or slide a person across surfaces. Get help or use a lift sheet to turn and move a person in bed.
 - Do not elevate the head of the bed more than 30 degrees. This will prevent sliding in bed and reduce pressure on the tailbone.
 - Prevent the person from sliding down in the wheelchair.
- c. **Protect skin where bones protrude and where two skin surfaces rub together:** Protect the skin with clothing and special pads for elbows and heels. Cushions do not replace frequent positions changes.
- d. **Protect fragile skin from being scratched:** Keep fingernails (yours and the person's) and toenails short. Long toenails can scratch a person's legs.
- e. **Protect skin from moisture and irritants:** Keep skin dry. Be aware of moisture sources, including baths, rain, perspiration, and spilled foods and fluids. Watch for skin irritation from detergent residues left in clothing and bedding.
- f. **Watch for allergic reactions (rashes) from health and personal care products:** Some persons, for example, are allergic to incontinence pads.
- g. **If you see an area is reddened,** provide a light massage **around** the reddened area (not on it), to increase circulation to the area.

E. BATHING, DRESSING, AND GROOMING

1. Skin Care

In general, skin care involves good hygiene, good nutrition, exercise, and preventive measures. It is important to regularly inspect the person's skin for signs of infection or breakdown. Refer to the previous section for more details on prevention of skin damage. As mentioned before, prevention is better than treatment. A DCW needs to be observant to reduce the risk of problems later on.

Facilitator Notes: Skin care tips

- **Aloe Vera gel** (the green gel in the first aid aisle—not the lotion) is very good for use on minor skin irritation such as chafing between the legs, groin folds, or under the breasts. Use as directed. Make sure aloe is listed as the first ingredient. Cheaper products will list water as the first ingredient.
- If a woman does not wear a bra and has large breasts, use a clean piece of 100% cotton material such as a man's hankie or piece of undershirt and place under the breasts after her shower. It will help to keep the skin dry.
- Medicated powder may also work well on minor skin irritation.
- Use lanolin based soap instead of antibacterial or heavily scented soaps. A rinseless soap also works well.

2. Bathing

Bathing provides many benefits:

- Cleansing and removing wastes from the skin.
- Stimulating circulation.
- Providing passive and active exercise.
- Helping a person feel better about him/herself and his/her appearance.
- Providing an opportunity to observe the skin and an opportunity to connect with the person.

Some individuals may be able to bathe without help. Some may need assistance occasionally, and others may need help all of the time. **Encourage as much independence as possible.**

How often a person bathes will probably be between you and the person. A minimum of twice a week is recommended. You should realize that every time an individual bathes he/she washes off natural oils, making the skin drier. The person's bathing patterns, skin type, recent activities and physical condition will all be factors in deciding how often a person bathes.

Provide for safety and comfort:

Note--Tub baths are not recommended for people with certain disabilities or elderly persons because it increases the risk of falls or not being able to get out of the tub.

A rule of thumb: If an individual cannot get in and out of a tub without assistance, then a shower should be done using a shower seat. This is safer for not only the person but the DCW as well. Notify your supervisor if this is an issue.

Assisting with Shower or Bath

It is important to determine the amount of assistance for bathing or showering the person you are supporting requires. The support plan may provide some guidance. You should also discuss directly with the person or family the amount of assistance and supervision the person requires.

After learning the person's individual needs during bathing or showering:

- Find out what skin care products the person uses and gather all bath items needed before starting.
- Allow or assist the person to use the toilet prior to bathing, if needed.
- Protect the person's privacy.
- Always explain to the person what you are going to do.
- Protect the person from falling.
- Use proper techniques when lifting or transferring.
- **Always** check the water temperature before using.
- When providing total assistance with the bath or shower, always start at the head and work down to the feet.
- Encourage the person to help as much as is safely possible.
- Rinse the skin to remove all of the soap.
- If assisting to dry the person, pat the skin dry to avoid irritating or breaking the skin.
- Assist with or bathe the skin whenever feces or urine touch the skin.

Safety measures for tub baths and showers

- Place a mat on the shower floor unless there are non-skid strips or a non-skid surface.
- Drain the tub before the person gets out; cover the person's upper body with a towel for warmth.
- Have the person use safety bars when provided.
- Avoid using bath oils.
- Verify and always provide the amount of supervision the person requires.
- Do not leave weak or unsteady persons unattended.
- Stay within hearing distance of the shower or tub if the person can be left alone by waiting outside the shower curtain or door.

3. Hair Care

Routine hair care involves washing, combing, drying and styling. It can be a very tiring task, even for persons who are independent in most areas. A person may enjoy going to a hair salon or barbershop, or having you assist. Some hairdressers will make house calls, too.

A shampoo can be given in the tub or shower, at the sink, or in bed. Always consider the person's wishes when determining a style. It should be easy to care for and appropriate for the person. The person's own styling equipment (e.g., styling brush, curlers, and hairpins) should be used.

If you assist with hair care, have the needed supplies ready:

- Shampoo, cream rinse or conditioner.
- A plastic container (for rinsing).
- Towels.
- Comb, brush, and possibly a hair dryer.

Caution: If the person has an eye disorder or has had recent eye surgery, consult a health care professional before proceeding with a shampoo. Moving the head into various positions might cause increased pressure on the eye. You may need to avoid this.

4. Dressing

The key to assisting with dressing, as with any of the personal hygiene and grooming tasks, is for a DCW to allow a person to be as independent as possible, even if the person dresses slowly.



Procedure: Assisting with Dressing

Supplies

Articles of clothing client wishes to wear.

Description of procedure

1. Communicate with person about the assistance procedure and expectations.
2. Provide for person's comfort and privacy.
3. Discuss person's preference of clothing. Offer the person a choice of what they want to wear that day.
4. Retrieve the clothing, and lay it out in an orderly fashion.
5. Dress weak side first (if applicable). Put the clothes on the weaker arm and shoulder side first, then slide the garment onto the stronger side. When undressing, undress the strong side first.
6. As much as possible, dress the person while seated. Put on underwear and slacks only up to the client's thighs. To finish, ask him/her to stand, or assist to stand, and then pull up the underwear and slacks.
7. Continue to communicate each step in the process as you go along.

Practical tips

- Always discuss with the person what their preferences are and how they are most comfortable.
- Don't assume a person wants to wear items of clothing that someone else may have chosen for them.
- Be aware of how the person may be feeling about needing assistance.
- Be aware of any issues that could cause the person to get tired or frustrated easily.
- Be pleasant while completing this task, engage the person in conversation.
- Encourage the person to wear clothes with elastic waistbands and Velcro closures.

Don't forget!

- Encourage the person to be as independent as possible.
- Only provide the assistance needed – don't do everything for the person just because it is faster for you.
- If the person has a stronger and a weaker side, put the clothes on the weaker arm and shoulder side first, then slide the garments onto the stronger side. When undressing, undress the strong side first.

5. Shaving

For most men, shaving is a lifelong ritual, and they are able to perform this task despite impairments. The act of shaving, as well as the result, usually boosts morale. A male person should be allowed to shave himself unless it is unsafe for him to do so.

A female person may desire to have legs, armpits or facial hair shaved.

An electric razor is easiest and safest to use. Persons who have diabetes or who take anticoagulants should use an electric shaver. After shaving with the electric shaver, rinse the face with warm water or place a warm wet washcloth over the face and pat dry. If the individual desires, apply after-shave lotion.

6. Nail Care

Nail care for fingers and toes prevents infection, injury, and odors. Hangnails, ingrown nails, and nails torn away from the skin may cause skin breaks. Long or broken nails can scratch the skin or snag clothing. Nails are easier to trim and clean right after soaking or bathing. Nails are trimmed with nail clippers, not scissors. **Some agencies do not allow their staff to clip nails** because using clippers can cause damage to surrounding tissue.

Supplies

- Wash basin with warm water.
- Nail clippers (not scissors).
- Orange stick, emery board or nail file.
- Lotion or petroleum jelly.
- Paper towels.

Procedure

1. Arrange items next to the person. Allow the person to soak nails for 10-20 minutes or do the procedure after a bath. Clean under the nails with an orange stick.
2. Clip nails **STRAIGHT ACROSS** with the nail clippers **if allowed to do so**. Shape fingernails with an emery board or nail file.
3. Apply lotion or petroleum jelly to hands and feet.
4. Clean and return equipment and supplies to their proper place. Discard disposable items.

Do not trim (cut or clip) nails if a person:

- Has diabetes
- Has decreased circulation to the legs and feet
- Takes drugs that affect how the blood clots
- Has very thick nails or ingrown toenails

In these cases, nails should be **filed only** to prevent possible cutting of the skin. If more care is required, a podiatrist should be consulted (usually covered by insurance for the cases listed above).

Soaking the Feet and Assisting with Foot Care

Soaking the feet can help a person in three ways: it promotes relaxation, provides exercise, and allows for a DCW to examine the person's feet. **Caution: Soaking is not advisable for all persons.** Those with diabetes should not soak their feet. Consult your supervisor to be sure this procedure is recommended. General guidelines for soaking and caring for feet are:

- Schedule soaks on non bath days. The person can soak feet while sitting and doing grooming tasks or while watching TV. The foot soak should not last more than 20 minutes.
- Provide a basin of warm water and mild soap.
- Remind the person to exercise feet while soaking. Give step-by-step instructions: Wiggle the toes, stretch the feet, rotate the ankles clockwise, then counterclockwise, flex and extend the toes and ankles
- Pat feet dry. Dry thoroughly between the toes.
- Examine the feet. Look carefully, especially if the individual limps, resists walking or paces (increased friction may cause blisters or pressure sores). If any lesions are noted contact your supervisor for further instructions.
- Apply lotion to dry, cracking skin. Use a lotion containing lanolin or mineral oil.
- Clean and return equipment and supplies to their proper place. Discard disposable items.

7. Assistive Devices

Falls in the bathroom are the most common household accident. Wet, soapy tile, marble, or porcelain surfaces in bathrooms can be very slippery. A seat designed for the bath or shower and grab bars allow the person to enjoy safely bathing in comfort. Seats come in different sizes and styles. In any case, look for one that is strong, stable, and has rubber caps on the legs to prevent slipping.

Bath Stool

Economical and lightweight, the bath stool is suitable for a person of slight to medium build. The rubber-capped legs prevent slippage and, with no backrest, allow for easy

access to a person's back. The bath stool is ideal for narrow tubs and can easily be stored when not in use. However, its small base contributes to poor stability.

Bath Chair

The bath chair is good for a person with poor back strength and a bigger build (some seats can support up to 400 pounds). While stability is enhanced by rubber-capped legs and a wide base, the bath chair may not fit inside a narrow tub. The backrest hinders easy access to a person's back and other parts of the body.

Transfer Bench

A bench is suitable for those who have difficulty lifting their legs in and out of a tub. The long stationary seat remains partly inside and outside the tub. A person sits down outside the tub, and moves inside by sliding the body across the seat. The suction cups on the height adjustable legs (the inside of the tub is higher than the outside) prevent slippage.

Hand Held Shower Heads

Standard shower heads can be replaced with a hand-held model. This shower head allows an individual to hold the water at the level needed in the shower.

Grab Bars

Installing grab bars in the tub and shower can help a person get in and out more easily and reduce risk of falling.

A grab bar near the toilet can give support when sitting down and standing up. If more support is needed, there are a variety of railings that can be added to the toilet itself.

Raised or Elevated Toilet Seats

Raised toilet seats assist persons who have difficulty bending or sitting by raising the height of the toilet seat to a more comfortable and convenient height. There are a variety of raised toilet seats to choose from. Some have armrests which provide a sturdy grabbing platform to help with transfers and others are specifically designed for people who are recovering from hip replacement or leg fractures. Some can be attached to the toilet while others are freestanding.

The person must be able to have both feet flat on the floor when sitting on the seat, or it is too high.

F. ORAL HYGIENE

Good oral hygiene prevents sores and bad breath and keeps mucous membranes from becoming dry and cracked. Poor oral hygiene can contribute to poor appetite, and the bacteria in the mouth can cause pneumonia. Inflamed gums also set up an inflammatory process that puts a strain on the heart and decreases resistance to infections. Encourage persons to brush their teeth daily, especially at bedtime. Electric tooth brushes or brushes with larger or longer handles promote self-care.

Providing proper oral hygiene for an individual that is unable to care for his or her own teeth is an important role for a Direct Care Worker. Proper tooth brushing techniques help prevent conditions such as gingivitis, tooth decay and tooth abrasions, a condition in which the tooth is worn away. If you assist a person with oral hygiene, examine the mouth on a regular basis for signs of redness, swelling, or bleeding. A dentist should check any red or white spots or sores that bleed and do not go away within two weeks.



Procedure: Assisting with oral care

Supplies

- An extra soft or soft bristled manual toothbrush.
- Toothpaste.
- Protective gloves.
- Emesis basin.
- Disposable cup.
- Water or mouth rinse.
- Protective covering for clothing.

Description of procedure

1. Gather all needed materials.
2. Provide an explanation of what will occur prior to starting the process and continue throughout.
3. Place the person in a seated (minimum of 60 degrees) or standing position prior to beginning.
4. Place a protective covering over the person's clothing.
5. Wash hands and apply gloves before brushing the person's teeth.
6. Apply water and a small amount of toothpaste to the toothbrush.
7. Brush all surfaces of the teeth and gum line before brushing the inside of the teeth. It is a natural reaction to bite down on whatever is placed in the mouth. To help avoid the bite reflex, do not insert the toothbrush to the inside of the mouth until later in the process.

8. Offer the person the opportunity to rinse and spit into an emesis basin as needed. If the person cannot independently rinse, turn the person to one side to allow the liquid to run from the person's mouth into a folded cloth.
9. Rinse the toothbrush periodically and apply another small amount of tooth paste as needed.
10. Clean the inside and outside teeth.
 - Place the toothbrush parallel to the inside of the person's teeth.
 - Point the bristles at a 45 degree angle in the direction of the gum line.
 - Brush a small group of teeth at a time with a slow gentle motion for approximately 20 brush strokes or 10 seconds.
 - Continue above steps until all outside and inside upper and lower premolars and molars have been brushed.
 - Clean the inside surfaces of the upper and lower front teeth, use the tip of the toothbrush in a sweeping motion and move the toothbrush away from the gum line.
11. Upon completion, clean and dry the area around the person's mouth and remove protective covering.
12. Dispose of soiled linen and trash.
13. Remove and dispose of gloves.
14. Wash your hands.

Practical tips

- Stand behind the person so you are looking down on his/her mouth. This will allow easier access and a better view of the person's mouth.
- Don't use too much toothpaste.
- Brush all three areas of the teeth (outside, inside and top).
- Allow the person an opportunity to rinse as often as needed.
- If the person is not able to spit out water, use an oral swab instead of a toothbrush.

Don't forget!

- Thoroughly clean the toothbrush after each use.
- Start with the outside of the teeth.
- Utilize universal precautions and infection control measures through the process.

G. USING THE RESTROOM

Your responsibility is to help persons maintain normal function or be able to compensate for lost function. You must also do so in a professional manner that preserve's the person's dignity. Ensure privacy and comfort, and do not rush the individual.

Problems with elimination may occur due to a variety of reasons. Age-related changes, emotional stresses, and chronic diseases that disturb mental health, affect nutrition and limit activity are all possible causes. Bowel and urinary problems may be intermittent or may be constant, depending on the cause. The physical and emotional costs of bowel and bladder control problems can include:

- Increased risk of skin breakdown and infections.
- Feelings of anxiety, shame, embarrassment, self-reproach and frustration.
- Decreased sense of control, dignity, and self-esteem.
- Concern about the future.
- Threatened self-image.
- Loss of privacy to perform private functions.
- Social isolation.

1. Urinary incontinence

Urinary incontinence is the involuntary leakage of urine from the bladder.

Common causes for bladder problems:

- Nerve changes. The person does not recognize that the bladder is full.
- Memory loss. A person may forget where the toilet is or how to use it.
- Stress or fatigue.
- Infection.
- Medications.
- Alcohol.

Facilitator Notes:

Common bladder problems can be caused by reduced bladder capacity, a weakened bladder sphincter muscle, and decreased bladder muscle tone are all common. Other bladder control causes can be:

- Neurological changes. Nerve signals to the brain that the bladder is full are slowed, giving the person less time to reach the bathroom.
- Mental impairment. For example, memory loss can affect a person's ability to find the toilet and remember proper toileting procedures.
- Psychological changes. Depression, stress and fatigue can reduce the individual's motivation and ability to remain continent.

- Infection. Bladder infections are common among women.
- Medications. Diuretics increase urine output. Sedatives reduce awareness of the need to urinate.
- Alcohol. Alcohol increases urine output and reduces awareness of a full bladder.

Types of incontinence -- The four major types of urinary incontinence are:

- Stress incontinence: Leakage of urine during exercise, coughing, sneezing or laughing.
- Urge incontinence: Involuntary bladder contractions or the bladder sphincter opens with a sudden urge to urinate. The time between the brain sending the urge signal and the bladder sphincter opening is shortened leading to less time to make it to the bathroom.
- Overflow incontinence: Leakage of small amounts of urine from a constantly full bladder. This commonly occurs in men who have enlarged prostate glands and people who have diabetes.
- Functional incontinence: Problems with the functional or physical ability to get to the bathroom in time. It commonly occurs with conditions such as stroke, memory loss and Parkinson's disease. Persons who have normal control are not considered incontinent if a mobility disorder keeps them from reaching the toilet before urinating.

Control of incontinence

- **Establish toileting schedule every two hours.** Schedule trips to bathroom 10-15 minutes before the typical time incontinence usually has occurred in the recent past. Emptying the bladder before the urge allows more time to get to the bathroom.
- **Identify assistance you can provide.** For example, if access to the bathroom is a contributing factor, list steps you need to take to correct the situation (e.g., provide the person with a urinal or commode in the room, and label the bathroom door so that a confused person can identify it). Additionally, include interventions that may help a person (e.g., positioning, increased fluid intake, and exercise). The following practices are safe in most situations:
 - **Recommend the person wear clothing designed for easy removal.**
 - **Remind in an appropriate manner.** For example, use words in the person's vocabulary. A memory-impaired person may remember childhood terms such as "potty." If such terms are used, be sure everyone understands this is not meant to demean the person, but rather to help.
 - **Provide plenty of fluids, unless doctor's orders say otherwise.** A full bladder sends stronger messages to the brain. Also, adequate fluids dilute urine, making it less irritating to the bladder wall. Offer a glass of prune juice at bedtime if constipation is a problem.
 - **Encourage complete emptying of bladder before bedtime** and immediately after getting up in the morning.

2. Incontinence pads

Incontinence pads and briefs help manage bladder and bowel incontinence. They are very absorbent and protect clothing. There are many different types of pads and briefs on the market. If the person is unhappy with a certain type, try others before giving up. Please do not use the term “diaper” with adults.

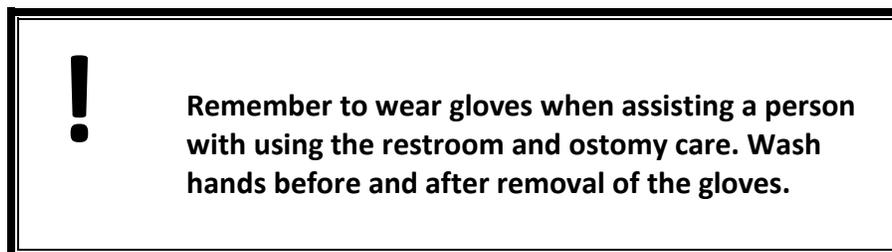
In assisting with changing a pad or brief, the DCW should gather supplies (new pad, plastic bag, and cloth or disposable wipes for cleansing the skin). The DCW should put on gloves and assist in removing the old pad as necessary. Put the soiled pad into the plastic bag. Assist the person in cleansing the peri area (the skin needs to be cleansed of urinary and fecal enzymes that will break down skin). Place any soiled disposable wipes in the plastic bag. Assist in applying a new pad. Peel off gloves and toss into plastic bag. Tie bag and take to outside trash. Wash hands.

3. Ostomy care

An ostomy is a surgical opening in the abdomen through which waste material discharges when the normal function of the bowel or bladder is lost. An **ileostomy** is an opening from the small intestine (ileum portion), and a **colostomy** is an opening from the large intestine (colon). Both types discharge feces. A **urostomy** is an opening to bypass the bladder and discharge urine.

The care and management of the ostomy depends on what type it is. Typically, the person wears a plastic collection pouch. It is attached to the abdomen at all times to protect the skin and collect the output. When a new pouch is needed, the skin is cleansed with soap and water, a protective skin barrier may be applied, and a new pouch is applied (may have to be precut to fit the stoma opening). The pouch is emptied at the person’s convenience. Again, how the pouch is emptied will depend on the type of ostomy and the supplies used. Some colostomies can be controlled by irrigation (enema) and only require a small gauze pad or plastic stick-on pouch to cover the stoma between irrigations.

There are different types of ostomy supplies on the market and each individual will have individualized needs for ostomy care depending on the type of ostomy and the size of the stoma (opening) and personal preference. Notify your supervisor if ostomy care is needed.



4. Skin Care after Using the Restroom

Skin care after assistance with using the restroom is extremely important. As has been mentioned previously, the enzymes contained in urine and fecal matter can cause skin irritation and rashes. These are similar to diaper rashes in infants. For individuals who are incontinent, a daily shower is advisable.

It may also be necessary if the person wears incontinence pads (do not use the term “diapers” unless it is an infant) to apply some type of skin protectant to the buttocks and peri area such as A&D ointment.

(Note: More detailed information can be found in [Colostomy Guide](#), a publication of the United Ostomy Association. Contact UOA at 1-800-826-826.

http://www.uoaa.org/ostomy_info/pubs/uoaa_colostomy_en.pdf.)

Facilitator Notes:

- Have participants practice the following skills
 - Assistance with brushing teeth
 - Assistance with eating
 - Assistance dressing

Optional activity

- Break the class up in small groups have each group take an ADL skill
 - Bathing
 - Dressing
 - Grooming
 - Oral Hygiene
 - Using the restroom (toileting)
- Have participants list and present techniques for the above listed ADLs that promote independence while ensuring that the person’s preferences are respected.

H. TRANSFERRING

Facilitator Notes:

A move as basic as getting in and out of a chair can be difficult for an individual with a disability, depending on her / his age, flexibility, and strength. Techniques for assisting an individual with transfers can vary. Some persons require a high level of assistance, also called maximum assist. The DCW will have to use assistive devices, such as a gait belt or a mechanical lift. Other persons will need less assistance, making the devices optional. The height and stability of the chair or other sitting surface also plays a role in the successful transfer. A slightly raised seat is preferable to one that is low or deep. A chair that has armrests is also preferable.

Some persons need assistance with transfers. Examples are getting in and out of bed or a chair.

There are different techniques and tools for the DCW to use.

Levels of assistance in transfers

- **Maximum assist**
 - Mechanical lift.
 - Gait belt with person who is 50% or less weight bearing.
- **Moderate assist**
 - Gait belt with person who is 50% or more weight bearing.
 - Verbal cues with moderate physical assist.
- **Minimum assist**
 - Gait belt optional.
 - Hands on with person who is 85 - 90% weight bearing.
 - Verbally and physically guiding the client.
 - Stand by assist (this is to ensure safety).

General guidelines for assistance with transfers

While procedures can vary for certain kinds of transfers, there are general guidelines that apply when assisting with any transfer.

- Explain each step of the transfer and allow the person to complete it slowly.
- Verbally instruct the person on the sequence of the transfer. (e.g., "Move to the front of the chair," etc.).
- When assisting in the transfer of a person **do not** grab, pull or lift by the person's arm joints (elbows, shoulders, wrists) as this can cause a joint injury.
- Know your limits: Don't transfer anyone heavier than what you can handle.
- If the person is unable to stand or is too weak to stand, the DCW should use a mechanical lift for transfers. If this is not in the service plan or you do not know how to use a mechanical lift, ask your supervisor for instructions on what to do.



At no time should the person put her or his hands around the DCW's neck during a transfer

1. Principles of body mechanics for back safety

Using correct body mechanics is an important part of a DCW's job because:

- The individual who needs support depends on the DCW for hands-on assistance. If the DCW does not take care of his/her back with the correct body mechanics, the DCW will not be able to provide that assistance.
- Not using correct body mechanics puts the safety of the person and DCW at risk.
- Some injuries cause permanent disabilities.

Just as lifting, pushing, and pulling loads can damage your back so can bending or reaching while working in an individual's home. As a DCW, you may have witnessed firsthand the pain and misery a back injury can cause. The good news is that you can learn some simple ways to reduce the risk of injuring your back.

Body mechanics principles that play an integral part of this section are:

- **Proper footwear:** DCWs should always wear proper footwear. Wear closed, non-slip shoes.
- **Center of gravity over base of support:** It is important for the DCW to be aware of center of gravity over base of support in working with a client. Usually a person's center of gravity is right behind a person's navel (belly button). A good base of support is being in a standing position where the feet are slightly apart and knees slightly bent.
- **Principles of body leverage:** Using leg and arm muscles is important, but so is applying body leverage. Mirror posture of the client. Use body as a whole and not just one part.

2. Use of a gait belt

A gait belt, sometimes called transfer belt, provides the DCW with a secure point to hold while assisting persons in walking and transfer activities.

Special Note:

Ensure the person can safely wear a gait belt. You may not be able to use a belt for:

- Persons with recent surgery or incisions (within the last 6-8 weeks) in the torso area.
- Individuals with ostomy (e.g. a colostomy), G-tube, hernias, severe COPD, post-surgical incisions, monitoring equipment, tubes or lines that could become compromised by the pressure.
- A pregnant person. Applying a gait belt to a pregnant woman could cause injury to the unborn child.

If the DCW determines the person cannot safely use a gait belt, the DCW should contact the supervisor for instruction on agency specific policy and procedures.

Procedure: Use of Gait Belt

Supplies:

Gait Belt (with metal teeth or quick release buckle).



Description of procedure

1. Tell the person what you are going to do.
2. Position the person to make application of the belt easier. The person needs to move forward and sit on the edge of the chair.
3. Place the gait belt around the person's waist, above the pelvic bone and below the rib cage. Always place the gait belt on top of clothing, and for females make sure breast tissue is above the belt.
4. Pass the metal tip of the belt end through the teeth of the buckle first and then through the other side of the buckle.
5. Adjust it so it is snug, but not uncomfortable for the person. You should be able to slip your open flat hand between the belt and the person.
6. Tuck the excess end of the belt through the waist band.
7. The strap should lay flat across the buckle.
8. ALWAYS verify proper closure before use.
9. ALWAYS grasp the transfer belt from underneath.
10. Remove the gait belt when not in use, or loosen it.



Practical Tips:

- It is important that you ask permission before applying a gait belt because you are about to invade the person's personal space. Maintain person's rights by informing him/her of all procedures prior to actions.
- Gait belts come in various lengths; use an appropriate size for the person.
- Belts with padded handles are easier to grip and increase security and control.
- Use a rocking and pulling motion rather than lifting when using a belt.
- DCW should walk slightly behind the person with a hand under the bottom of the belt.
- On some gait belts, the seam and label will be on the outside, on other belts it is on the inside. Don't assume that the manufacturer's label is on the inside – be sure to start putting the end of the belt through the teeth first.

Don't forget!

- Apply gait belt over clothing, NEVER apply to bare skin.
- Check female persons to assure no breast tissue is caught in belt.
- Use good body mechanics when transferring a person with a gait belt.

3. Procedure: Transfer out of bed to a standing position

Supplies

Non-slip shoes/socks.



Description of procedure

1. Tell the person what you are planning to do.
2. If possible, raise or lower the height of the bed to prevent a position that could strain the DCW's back.
3. Have the person roll onto their side, facing you, elbows bent, knees flexed.
4. Place one arm around the person's shoulders (not the neck) and one over and around the knees.
5. Instruct person to use the forearm to raise up and the opposite hand to push up to a sitting position while you support their back and shoulders with left hand.
6. With your hand behind the person's knees, help them swing their legs over the side of the bed with one fluid motion. Assist them in moving to the edge of the bed if necessary.
7. Allow person to sit on the edge of the bed for a minute or two. Ensure the person is oriented and stable before attempting to stand
8. Assist with putting on non-skid footwear (sneakers, slippers, tread socks are good choices).
9. If bed was raised or lowered, make sure to adjust to a height in which the person's feet can touch the floor comfortably
10. Instruct person to place feet flat on the floor.
11. Assist the person to stand. The DCW should keep one hand on the person's elbow and the other behind the person's back.

Practical Tips

- Be sure to have supplies ready. Do not leave the person on the edge of the bed while you go find slippers or a robe.
- Remember to support limbs and back during procedure.

- **BE OBSERVANT!** It is common for the blood pressure to drop when going from a prone to a sitting position, causing light-headedness or dizziness. Watch the person for changes in condition, such as color changes, respiratory changes, and other signs of distress.
- Use good body mechanics when turning a rolling, moving, and standing. Protect your back.
- Encourage the person to help as much as he possibly can; this helps maintain independence.

Don't forget!

- Don't forget to lower the bed if a mechanical bed is being used.
- Do not "pull" the person by arms, hands, wrists etc. Support back and knees to prevent injury.
- Do not let the person place his hands/arms around your neck while you assist.

4. Transfer from wheelchair

Supplies:

- Wheelchair.
- Gait belt.
- Chair.



Description of procedure

Note: Person is 50% or more weight bearing (moderate assist)

1. Ensure the person can safely wear a gait belt.
2. Explain the gait belt procedure to the person.
3. Ask the person's permission to use the gait belt. Explain the belt is a safety device and will be removed as soon as the transfer is complete.
4. Tell the person what you are going to do.
5. Lock the wheels of wheelchair.
6. Put the footrest in the up position and swing the footrest to the side or remove.
7. Take off the armrest closest to the chair (or drop armrest if possible).
8. Place chair at a 45 degree angle to the wheelchair.

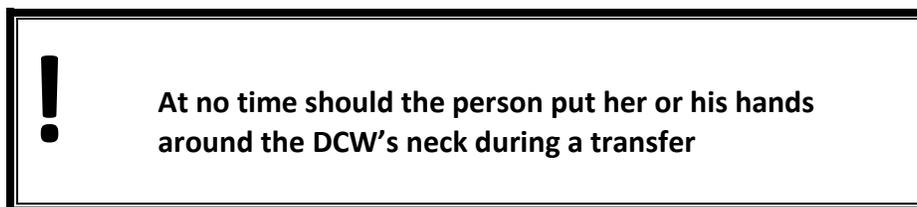
9. Have the person move to the front of wheelchair seat.
10. Use gait belt secured around person's waist to assist him/her out of the wheelchair (refer to gait belt skill).
11. Foot Placement (depending on the client's disability or preference):
 - Place both of your feet in front of the client's feet with your toes pointed outward.
 - Place one foot slightly in front of the other one. The foot in front will be placed between the client's feet.
12. Have the person either hold onto your shoulders or arms, not around your neck!
13. Grasp the gait belt on both sides with fingers under belt.
14. Bend at knees and hips. Lift with legs, not back.
15. Assist the person to a standing position, mirroring posture of person.
16. Have the person stand for a minute, shifting weight from one foot to other.
17. Pick up your feet and move them facing the chair as the person takes baby steps to a standing position in front of chair.
18. Ask the person if he/she feels the chair seat on the back of his/her legs.
19. Have the person put his/her hands on the armrests.
20. Assist the person to a seated position, mirroring the person's posture.

Practical Tips:

- DCW should always use proper foot wear (closed, non-slip, flat shoe).
- Use smooth fluid motion.
- Don't rush the transfer procedure.
- Don't transfer a person who is too heavy for this type of body transfer.

Don't forget!

- Keep body in proper alignment; use proper body mechanics.
- Move feet with the pivot, do not twist.
- Be sure to place gait belt properly.



5. Assistance with ambulation (Walking)

Ambulation simply means to walk or move from one place to another. It is important to understand that every person will be different in his or her level of need for assistance.

There are several benefits to ambulation, some of which include:

- Relieve stress and anxiety.
- Improve and/or maintain muscle strength.
- Improve circulation.
- Decrease digestion and elimination problems.
- Improve appetite.

Special Note:

- Before you begin working with a person, familiarize yourself with the support plan and expectations/requirements. Contact your supervisor for clarification.
- Ensure the person can safely wear a gait belt. See “application of gait belt” for procedure and contraindications.

Supplies

- Gait Belt and/or other walking aids like a cane or a walker.
- Non-slip, properly fitting footwear.



Description of Procedure

1. Communicate procedure/actions to person before you begin.
2. Apply non-skid, properly fitting footwear.
3. Apply gait belt (see procedure for gait belt application).
4. Make sure that the person has his feet firmly on the floor.
5. Use an underhand grasp on the belt for greater safety.
6. Have the person’s walking aid readily available if required.
7. Walk behind and to one side of the person during ambulation; hold on to the belt from directly behind him. Be aware to support weaker side if applicable.
8. Right side: you should be standing between 4 and 5 o’clock.
9. Left side: you should be standing between 7 and 8 o’clock.



10. Let the person set the pace, and walk in step with the person, maintaining a firm grasp on gait belt.
11. Watch for signs of fatigue.

Ambulation with a walker

When assisting a person with ambulation when using a walker, it is imperative that the person stay inside the frame of the walker. Make sure it has been properly fitted for the individual. The DCW should always walk on the person's weak side to provide additional support as needed.

Special Note: In the instance a person does collapse or loses his/her footing, it is acceptable to ease the person gently to the floor. The DCW should not try to carry the person, hold him up or catch him if he starts to fall.



Practical Tips:

- Communicate expectations with person at all times.
- Encourage the person to assist as much as possible.
- Be aware of/remove tripping hazards: electrical cords, throw rugs, clutter.
- Make sure that you are standing on the person's weak side, if applicable.
- Be observant: the person may tire easily and can only handle short walks.
- Ensure assistive devices fit properly; notify your supervisor with concerns.
- The tips on the canes wear out over time and it may be necessary for them to be replaced periodically.
- Don't rush the person to meet your schedule.

Don't forget!

- Keep a firm grasp on gait belt.
- Don't assume that once the person is up and moving, she will continue to be stable. Always be prepared for a fall.

I. TURNING AND POSITIONING

Facilitator Notes:

A person sitting a long time may slide down in the chair. The DCW needs to assist the individual

with repositioning. A gait belt should be used when providing assistance. If the person is sitting in a wheelchair, make sure the wheels are locked before repositioning the individual. Even with good sitting position, the person should be encouraged to shift weight slightly occasionally. This can help prevent soreness and pressure ulcers on the skin.

When a person remains in bed for a long time, it is also important to turn and shift weight. Some individuals just need to be reminded; others need assistance. The person can alternate positions from being on the back (supine) to the side (lateral) or face down (prone). Some beds can be adjusted so that the head is higher (Fowler's position).

1. Introduction

Preventing pressure sores (Ulcers)

Some individuals spend much time in bed or in a chair or wheelchair. Some persons can shift or turn on their own, but others will need assistance.

The DCW is responsible for:

- Reminding the individual to change position regularly.
- Providing assistance when needed.
- After turning or after a transfer, ensuring proper positioning for the individual.
- People who cannot change position need to have the DCW change his/her position in bed or in a chair/wheelchair at least every two hours. (See also the section on skin care.)

Preventing contractures

Facilitator Notes:

A contracture is a stiffening of a muscle due to immobilization (unable to move). Following a stroke or other injury, muscles can remain inactive for long periods of time. During this period of time, the muscle atrophies: it gets smaller and shorter, sometimes to the point that it can no longer be used. Contractures can form in the hands, fingers, arms, hips, knees and calves, as well as other areas.

When a person with a disability is sitting, make sure she / he is sitting upright to prevent contractures from forming in the chest muscles and the front of the shoulders. Make sure that both feet are flat on the floor, and encourage the person to keep palms open and down in a relaxed manner, possibly against a table or armrest. This will prevent contractures from developing in the hand. Putting a rolled washcloth in the person's hand may help prevent hand contractures and will also help with hygiene.

Once a contracture has developed, it can be difficult and painful to treat. It severely restricts a person's movement and independence. **DCWs can help prevent contractures through proper positioning, exercise and equipment.**

A contracture is a stiffening of a muscle due to inactivity. When muscles get smaller and shorter, they cannot be used properly. Contractures can be painful and difficult to treat.

Tips for preventing contractures:

- Encourage the person to sit upright.
- Both feet should be flat on the floor.
- Hands should be open and relaxed.

2. Procedures for Turning and Positioning



Procedure: Positioning in bed

Proper alignment of a person while in bed can be essential to the person's comfort and proper rest. The DCW must conscientiously assist in maintaining good body alignment, proactively address pressure points and be aware to support the natural curves of the body. These curves need to be supported to prevent undesired pressure that may lead to uncomfortable areas or pressure sores.

Proper positioning:

- Helps the person feel more comfortable.
- Relieves strain.
- Helps the body function more efficiently.
- Prevents complications with skin breakdown and pressure sores.

Supplies

- Bed.
- Blankets.
- Pillows.

Description of procedure

1. Provide for person's privacy.
2. Communicate expectation/procedure to person (how is the person most comfortable, are there any pressure concerns, ask about personal preferences).
3. Raise bed to comfortable position, lower side rail (if mechanical bed is available).
4. Roll person to a new preferred comfortable position (support upper torso and head).
 - Supine: flat on the back.
 - Fowler's: on the back with head raised slightly.
 - Lateral: on either side.
 - Prone: on the stomach.
5. Place pillow under person's head for comfort.

6. The arms are extended and supported with small pillows, elbows may be supported and off the bed.
7. A rolled towel may support the small of the back.
8. A small pillow is placed along person's thighs and tucked under to prevent external hip rotation.
9. A small pillow placed under the ankles raises the heels off the bed.
10. The knees may be flexed and supported with a small pillow or blanket roll.
11. A small pillow or roll may be added at the feet to prevent foot drop.

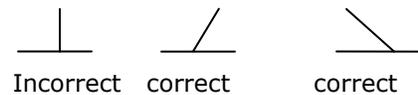
Positioning in Bed



Supine Position, on the back, with pillows used for support; heels off the bed—note pillow under head is placed under shoulders and under ankles, calves and knees.



Lateral Position, on the side, w/ pillows used for support-- person should not be placed at 90 degree angle (hip to bed) but rather slightly side lying either to front or to back



Procedure: Positioning in wheelchair

When a person with a disability is sitting in a wheelchair, make sure she/he is sitting upright to prevent the risk of pressure sores. A proper sitting position places the person in good, comfortable alignment. Good alignment involves head, shoulders, hips squarely over the axle of the wheel.

Incorrect position for front wheels



Correct position for front wheels



Description of Procedure

1. Explain to the person what steps you are going to do to reposition him.
2. Have wheel chair locked with caster wheels in forward position (this can be accomplished by moving the wheelchair backwards. Then the front caster wheels go forward, which sets the wheelchair to have a strong base of support.
3. Move foot rest to side if applicable.
4. Stand in front of the person with the left leg of the person between your legs. Have the person lean forward with the person putting his/her head above your left hip. This places most of the person's weight on his/her right buttock side. Your left arm should come across the person's back to provide stability.
5. Place your right arm under the thigh of the person's left leg while placing slight pressure against the person's left knee by pressing against it with your leg. (It is best to use the wide area above your knee to press against the person's knee.) With a fluid motion, use your entire body to gently push the person toward the back part of the wheelchair.
6. Let the person sit up, and then do the same steps to the other side of the person that needs to be repositioned. You might need to do this several times (both left side and right side) for the correct alignment of the person in the wheelchair.



Practical Tips

- Always explain to the person what is being done.
- Make sure wheels are locked.
- Make sure the person's weight is on the side opposite the side that is to be repositioned.
- Use your entire body when positioning.
- Prepare for this technique by repositioning yourself in a chair: Sit on the edge of a chair and move yourself backward without the use of your hand. This motion of backing up in a chair (first one side, then the other) is used for the technique of repositioning.

Don't forget!

- Always use proper body mechanics. Poor body mechanics can injure both DCW and person.
- Do not rush the procedure; you may need to do this procedure a couple of times to get the person all the way back in the chair.
- DO NOT lift person over the back of the handles of the wheelchair

Note: When doing this procedure with someone in a chair, make sure the back of the chair is secured so that the chair does not move when repositioning the person.

Practice Scenario

John, who is quadriplegic and uses a mechanical lift to be transferred into the wheelchair, regularly needs to be repositioned in the wheelchair to have a good sitting alignment. Demonstrate how you would reposition John if he is sliding out of the wheelchair.

3. Range of Motion (ROM) Exercises

Range of motion exercises are the best defense against the formation of contractures. A physical therapist, home health nurse or other health care professional should recommend helpful ROM exercises for an individual with disabilities to do at home. These exercises will concentrate on the joints. Each motion should be repeated, slowly and gently, and never beyond the point of pain. **Never exercise a joint that is swollen or red.**

Some individuals will be able to do ROM exercises independently; perhaps they need just encouragement and direction from you. Others will need assistance from you. This can mean helping them to lift, stretch and move limbs and joints, or being physically "cued" on how to perform the exercise. Still others, who are very limited physically, may be dependent on you to actually move them through the exercises. Regardless of how much you must be involved, the person will benefit from the movement: it will allow them to maintain more range of motion.

Active ROM exercises are done by the person.

Passive ROM exercises are done by the DCW. Passive ROM exercises should be approved by a health care professional to limit liability. Refer to the support plan or ask your supervisor for instructions before assisting with any exercises.

4. Assistive Devices

Walkers and wheelchairs are common devices to help individuals with mobility. The DCW should be familiar with the devices and know how to use them safely.

Facilitator note:

Older individuals may use a cane. See the appendix for more information on canes.

Walkers rank second behind canes in amount of users. Since their introduction over two hundred years ago, walkers have changed greatly. Walkers come in many models, sizes and styles. Wheel size and walker weight vary greatly in different models of wheeled walkers.

Walkers

Walkers are popular: almost two million people in the U.S. use them. Walkers are helpful for people with arthritis, weak knees or ankles, or balance problems. Able to support up to 50% of a person's weight, walkers are more stable than canes.

Types of walkers

The **standard walker** (no wheels, see photo on p. 41) is the basic type most often used in therapy. To operate, a person lifts the walker, moves it forward, and puts it back down with each step. Because they require lifting, extended use may cause strain on the wrists, shoulders, and arms.

With a **wheeled walker** (2 wheels), the user merely pushes the two-wheeled walker forward. No lifting is necessary, so the walking style is more natural.

Two-wheeled walkers have automatic brakes that work when you push down on the walker. Some have auto-glide features that allow the rear legs to skim the surface.

Many standard and wheeled walkers fold for easy storage or transport.

Rolling walkers (3 or 4 wheels) require less energy. Gliding over carpets and thresholds is easier, and they may make turning easier. Rolling walkers often have hand brakes. All are heavier than rigid or folding walkers. Many wheeled walkers do not fold and may be difficult to transport.

Effective walker use

- A professional, such as a physician or physical therapist, should help choose or prescribe a walker and then demonstrate how to walk correctly with it.
- Walker height is best when the arm bends at the elbow in a 20 to 30 degree angle. The top of the handle of the walker should be at the same height as the bend of the person's wrist.
- To prevent tripping or falling, the person should:
 - Always look ahead, not at the feet.

- Walk inside the walker (avoid pushing walker to far ahead as if it were a shopping cart).
- Use walkers only in well-lit areas. Cluttered and crowded areas, throw rugs, and wires running across the floor should be avoided.
- Wear appropriate footwear. Properly fitting shoes with rubber soles are best. Loose fitting footwear such as slippers, or slippery-soled shoes, should be avoided.
- Avoid using the walker on stairs.

Small rooms, such as bathrooms, may prevent safe walker use. A solution is to install grab bars. With a wheeled walker, you may be able to reverse the wheels. Then the wheels are on the inside of the walker, saving 3-4 inches of space.

Facilitator Note:

Individuals with developmental disabilities are fitted for their wheelchairs, if they need one. The same does not always apply for older adults, who may buy a used wheelchair. If not fitted properly, use of the wheelchair may be less than optimal. See the appendix for additional information.

Wheelchairs

Most common is the **standard wheelchair**. It can weigh over forty pounds. A light weight wheelchair (20-25 pounds) is easier to transport or store.

Power wheelchairs (electric) have batteries. They require little strength to operate. They can be heavy and large and probably require a van for transportation.

Scooters are also electric. A scooter looks like a chair mounted on a platform with wheels.

Wheelchair Accessories

- Transfer boards let a person move from the wheelchair to another seat or bed without standing.
- Safety flags make the person or chair more visible. It is a red flag on a long pole.
- Baskets and bumpers are available for some wheelchairs.

Activity:

Have participants practice the following skills:

- Assistance with ambulation / use of gait belt.
- Techniques for positioning a person (bed / wheelchair).
- Transfer in and out of a wheelchair.

Optional

Instructor Resources

Denture Care

Dentures need to be cleaned at least once a day to prevent staining, bad breath and gum irritation. Partial dentures require the same care as full dentures. If you perform this task for the person, follow this recommended procedure:

1. Wash your hands before and after handling dentures, and wear disposable gloves.
2. Use a tissue or clean washcloth to lift one end, break the suction, and remove the dentures from the person's mouth.
3. Observe the mouth for loose, broken teeth, sores, swelling, redness or bleeding. Any of these could indicate improper fitting dentures or a more severe mouth problem.
4. Place dentures in a container filled with cool water.
5. Clean dentures over a basin filled with water or lined with a washcloth, to prevent breakage should dentures be dropped accidentally.
6. Cup dentures in hand. Brush the upper inside first, then the tooth and palate area. Rinse thoroughly.
7. Have the individual rinse before replacing dentures. Provide a mouth rinse such as a saltwater (saline) solution. A warm saline rinse in the morning, after meals and at bedtime is recommended.
8. Apply denture cream or adhesive to dentures before replacing per individual preference.
9. Store dentures in water when not in the person's mouth. This keeps them from warping. Dentures should soak in water for 6 to 8 hours each day (usually overnight).



Procedure: The Bed Bath

Bathing is an activity of daily living that cleans skin, improves circulation, and provides an opportunity for range of motion and socialization. It is preferable to transfer the person to a chair to provide a partial bath or to a shower bench. When this is not possible due to person's weakness, decreased endurance (person cannot sit upright for an extended time), or respiratory problems that make transfers too taxing, then a bed bath needs to be provided.

Supplies

- Wash basin.
- Lanolin based soap (rinse-less soap works best).
- At least four soft, absorbent towels and two soft washcloths.
- Disposable gloves.
- Moisturizing body lotion.

Description of Procedure

1. Ask the person his/her preferences, and based on the response, gather supplies and plan how to proceed.

2. Explain what will be done and continue to talk to the person through each step of the bath.
3. Assist the person with removing clothing, eyeglasses, and jewelry.
4. Put on disposable gloves.
5. Cover person with two large towels, one covering the shoulders to waist and the other from the waist to the toes, then remove bedding underneath.
6. Use one washcloth for cleansing and another for rinsing (unless a rinse-less soap is used).
7. Have the person wash his/her face if able or wash the face making sure the areas behind the ears get washed and dried.
8. Place towel lengthwise under the person's arm. Wash, rinse and pat dry the arm, armpit, and hand (place the hands in the wash basin if possible).
9. Repeat with other arm, armpit, and hand.
10. Lift up the chest towel just enough to expose the chest and wash, rinse and pat dry. Re-cover the chest.
11. Lift up the towel covering the abdomen and wash the area to the groin. Rinse and pat dry. Replace the towel.
12. Change water as soon as it gets cold.
13. Place towel lengthwise under the person's leg. Wash, rinse and pat dry the leg and foot. Make sure area between the toes is dried. Check the heels for any signs of skin problems.
14. Repeat the same process on the other side of the body.
15. Turn the person on the side away from you.
16. Exposing just the back, place a towel lengthwise close to back.
17. Beginning at shoulders and working down toward buttocks, wash, rinse and pat dry the back. Examine area of tailbone for skin problems (this is a common problem site).
18. Turn the person on back. If the person cannot wash the genital area, do it for him or her, always wiping from genital to anal area (front to back). (See "Perineal care" below.)
19. Turn person on side. Wash the rectal area, front to back, rinse and pat dry.
20. Apply moisturizer while the skin is still moist.
21. Assist the person with dressing.

Perineal care

Peri-care is the term for cleansing the genital area. Be sure to provide for privacy and comfort. Close the door and pull the window-shade if necessary to preserve privacy. Use a towel or bath sheet to keep the person covered while you perform peri-care.

- **Female:** Have the woman lie on her back with knees bent. Visualize the area and separate the labia. With a washcloth make one swipe from front to back. Turn over the cloth and make another swipe from front to back. Continue until the area is cleansed. Rinse with water using the same procedure and pat dry.

- **Male:** Have the man lie on his back. If the individual is uncircumcised retract the foreskin. Grasp the penis and with a circular motion cleanse from the tip of the penis to the shaft. Turn over the cloth and repeat from the head of the penis to the shaft. Wash the scrotum. Rinse with water and pat dry. **For the uncircumcised male put the foreskin back into the original position.**
- **For rectal area for both female and male:** Have the person lie on the side away from you. If necessary separate the buttocks to visualize the anal area. Wipe from the front to the back, turning to a new area of the washcloth after each swipe until the area is clean. Rinse with water and pat dry.

Practical Tips

- Throughout the procedure the person should be encouraged to perform as much of the bathing routine as possible.
- The DCW should ensure privacy and dignity by only exposing the areas necessary during bathing. Close the door and pull the window-shade if necessary.
- Make sure the room is warm and draft free.
- Be careful not to overtire a person. If a person becomes too tired, finish up with the most important areas (face, hands, arm pits, and genitals) and leave the rest for another day.
- When washing the eyes, wipe one eye, turn the cloth and wipe the other so as not to contaminate the other eye. The same holds true for perineal care. On a female wipe front to back, turn the cloth and wipe front to back. Repeat until area clean.
- Do not scrub or rub, as this might bruise or abrade older skin.
- When applying moisturizer, gently massage bony prominences (e.g., hips, tailbone, elbows) using a light circular motion. Be observant for any skin changes. Do not massage legs—poor circulation often causes clots to form, which can be dislodged by massage.

Don't forget!

- Wash areas from clean to dirty, that is, from head to rectum. It is not as important whether you wash arm, leg, and then the other arm and leg or arm, arm, and leg, leg.
- Communication is very important before and during the procedure. This includes non-verbal communication during perineal care. If you feel uncomfortable or hesitant, the person will probably feel the same. Even if the person is non-verbal, continue to talk to the person.
- Keep water warm to aid in comfort. Cool water can cause the person to catch a chill.

Catheter Care

a. Indwelling (“Foley”) Catheter

An indwelling catheter is a long tube inserted into the bladder. It is inserted through the urethra, the normal opening of the bladder. It is important to reduce the risk of urinary tract infections. This is achieved by cleanliness in maintenance of the catheter, tubing, and drainage bags and by proper positioning of the tubing and

drainage bags. **Routine catheter changes are done by a nurse, but it is the responsibility of the DCW to notify a supervisor/nurse of any changes in the urine or complaints of pain.** The guidelines for care are:

1. Make sure urine is allowed to flow freely. Tubing should not have kinks or have anything obstructing its flow.
2. Keep the drainage bag below the level of the bladder while in bed, using a walker or wheelchair. Do not attach the drainage bag to the bed rail.
3. Do not set the drainage bag on the floor as this can contaminate the system.
4. Coil the tubing on the bed. Keep the tubing above the drainage bag.
5. Secure the catheter to the inner thigh with tape or catheter strap to reduce the friction and movement of the catheter at the insertion site.
6. Check for leakage of urine and report findings to your supervisor.
7. Cleanse the catheter insertion site when giving daily peri care and if needed after bowel movements and vaginal drainage using the procedure outlined below.
8. Drain the drainage bag in the morning and before bedtime and as needed.
9. Report any complaints of pain, burning, irritation, the feeling of a need to urinate or any changes in urine characteristics such as color, clarity, and odor to your supervisor

To cleanse the catheter at the insertion site:

Put on gloves. Separate the labia (female) or retract the foreskin (male). Check the catheter site for crusts or abnormal drainage. Holding the catheter in place with your fingers, cleanse the catheter from the meatus (urethral opening) down the catheter about four inches. Use soap and water. Avoid tugging on the catheter; pulling on the catheter can cause pain. Make sure the catheter is secured properly and continue with any further peri care. Replace the foreskin on a male to the original position.

b. Suprapubic Catheter

A suprapubic catheter is inserted through a permanent, surgical opening in the lower abdomen to the bladder to drain the urine. The catheter is then attached to a urinary drainage bag or a leg bag. The care remains the same as for the care for an indwelling catheter listed above.

c. External Catheter

An external catheter (also referred to as a buffalo, Texas, or condom catheter) is applied like a condom to the male's penis and then attached to a urinary drainage bag or leg bag. The tip of the penis should not rub on the interior of the catheter. The catheter needs to be changed every 24 hours and the penis washed and pat dried before applying a new catheter.



Procedure: Empty the drainage bag

A person with an indwelling urinary catheter will have some type of a urinary collection device often referred to as a catheter bag. This catheter bag will have to be emptied by the person or DCW on a regular basis using special attention to infection control practices.

Supplies

- Catheter bag (large bag that can hold 2000 cc of urine-sometimes referred to as nighttime drainage bag)
- Disposable gloves
- Collection container (can be urinal, small pitcher or comparable device)
- Optional: apple juice and leg bag (holds 600-900cc and usually used during the day for more mobile persons)

Description of procedure

1. Explain to the person what steps you are going to take.
2. Wash hands, put on gloves.
3. Place the drainage container below the level of the person's bladder.
4. Unhook the tube and open the clamp over the container (be careful not to touch the tube on the side of the container).
5. Drain the urine into the container, close the clamp, and refasten the tube to the urine bag.
6. Empty the contents of the container into the toilet.
7. Rinse the container and pour the rinse water into the toilet and flush.
8. Disinfect container, dry with paper towels and put away for storage.
9. Remove gloves and wash hands following proper procedure.



Procedure: Positioning of the Bed Pan

Regular, periodic elimination of body wastes is essential for maintaining good health. Persons who are confined to bed and who have restrictive ambulation must rely on the DCW to help them with this task. This often includes assisting the person with the proper positioning and use of a bedpan. It is important to understand and be able to demonstrate this skill properly. The DCW must be aware of the emotional concerns of the person, preserve their privacy and dignity in the accomplishment of this task while maintaining good personal hygiene as well.

Supplies:

- Bedpan and cover (if available)
- Toilet tissue
- Basin of warm water
- Soap

- Washcloth
- Disposable gloves
- Paper towels/protective pad
- Person, Volunteer to be positioned, for realism
- Mannequin/doll if volunteer is not available
- Towel
- Baby powder or corn starch (if available)

Description of procedure

1. Explain procedure/expectations to person.
2. Provide for person's privacy.
3. Assemble supplies, place all but protective pad on nightstand.
4. Wash hands, apply gloves.
5. Raise bed to comfortable position, lower head if elevated (if mechanical bed is available).
6. Place protective pad on bed or bedside chair.
7. Fold bedcovers back, raise the person's gown, or assist with lowering pajama bottoms.
8. Sprinkle bedpan with baby powder or cornstarch for ease in sliding on and off the bedpan. Placing a paper towel in the bottom aides in emptying solid waste and cleaning the bedpan later.

If the person can assist:

1. Ask person to flex their knees, place their feet flat on the bed mattress.
2. Ask person to lift their buttock. The DCW may assist by putting a hand on the small of the back and lifting gently and slowly with one hand.
3. Push bedpan downward into mattress and slide under person's buttocks.
4. To remove bed pan, roll person to side, pushing bedpan into the mattress, holding carefully so as not to tip or spill contents. Ensure contents of bedpan are covered with toilet tissue.
5. Assist person with hand washing or antiseptic cleanser if needed.
6. Replace clothing and bedcovers. Provide for safety and comfort.
7. Take to bedpan bathroom.
8. Empty contents into toilet, careful not to splash.
9. Rinse, disinfect, dry and store bedpan using proper infection control procedure.
10. Provide for person safety and lower bed.
11. Remove gloves and wash hands.
12. Communicate with person as to comfort and position as needed.

If the person cannot assist:

(Begin procedure as above #1-8)

9. Roll person onto side, away from DCW.

10. Push bedpan downward into mattress and roll person back onto bedpan.
11. Narrow end should face the foot of the bed.
12. Person's buttocks should rest on the rounded shelf of the bedpan.
13. Check for proper positioning to avoid spills, glance at bedpan from the top, between person's thighs.
14. Replace the bedcovers and raise the head of the bed (if applicable).
15. Place toilet tissue within reach.
16. Assure privacy and safety.
17. Remain close to hear when person calls to notify they are finished.
18. Bring tub of warm water/perineal care supplies back to bedside.
19. Assist with perineal care (cleaning) as needed if person is unable to do so.
20. Lower the head of the bed and remove bedpan.
21. To remove bed pan, roll person to side, pushing bedpan into the mattress, holding carefully so as not to tip or spill contents. Ensure contents of bedpan are covered with toilet tissue.
22. Assist person with hand washing or antiseptic cleanser if needed.
23. Replace clothing and bedcovers. Provide for safety and comfort.
24. Take to bedpan bathroom.
25. Empty contents into toilet, careful not to splash.
26. Rinse, disinfect, dry and store bedpan using proper infection control procedure.
27. Provide for person safety and lower bed.
28. Remove gloves and wash hands.
29. Communicate with person as to comfort and position as needed.

Practical Tips:

- Always discuss with person their preferences and how they are most comfortable.
- Remember to collect supplies in advance.
- Always maintain safety and privacy in the procedure (raise/ lower bed, put up rails).
- This is a good time to make skin assessments, looking for "hot spots."
- Encourage the person to help as much as she possibly can; this helps maintain independence.
- Stay close to hear when the person is done; don't leave them on the bedpan too long.
- Don't put soiled bedpan in night stand.
- Casual conversation with the person makes task more pleasant for the DCW and the person.

Don't forget!

- Discuss the procedure with the person. Don't just jump in and mechanically perform.
- Don't forget your gloves!
- Be sure to keep person covered and maintain dignity throughout procedure.
- Use good body mechanics when turning and rolling – protect your back.

- Don't forget to help the person with personal hygiene, such as washing the person's hands.

Practice Scenario:

Mrs. Chin is 86 and recently fell and fractured her hip. It was surgically corrected with pins and rods, but still causes her a lot of pain when she walks. The DCW's shift with Mrs. Chin starts at 7am, to assist her in getting up, personal care, dressing and breakfast. The first thing she wants to do every morning is use the bedpan.

Please demonstrate how you would assist Mrs. Chin to use the bedpan, using proper techniques.

Ambulation: Canes

The handle of the cane should be at a height that would be equivalent to where the person's wrist of his strong hand would fall if his hand was placed at his side when standing in an upright position. The person should be using the cane on his strong side, and the DCW should be walking on his weak side for assistance.

Metal is preferred over a wooden cane since wood can splinter or crack. The quad cane (with four feet), offers more stability to help the user maintain balance while walking.

Effective Cane Use

- The handle of the cane should be as high as the wrist of the hand opposite the person's weak side. While standing and holding the handle of the cane, the elbow should be at a 20 to 30 degree angle.
- A person should not use canes on stairs without using a handrail or the support of another person on the opposite side. Most quad canes and other wide base canes are not safe for use on stairs.
- It is better not to use canes on snowy or icy surfaces – they can slip. However, metal or rubber tips that grip the ice may give more protection against slipping.
- Tips on the end of cane legs provide traction and absorb shock, thereby cushioning the hand. Make sure the cane tips are not worn down. Replacement cane tips are readily available in larger drug stores.
- A wrist strap attached to the handle of a cane is convenient. It allows the hand to be free without having to set down the cane. It also prevents a person from dropping the cane.

Additional Information on Wheelchairs

Today, older Americans use more wheelchairs than any other age group. As the number of people using wheelchairs grows, so the dimensions, characteristics, and kinds of wheelchairs are becoming more diverse. Unfortunately, many people are not aware of the wide variety

of wheelchairs to fit different needs and only know about the standard, heavy-duty wheelchair.

Many people pick up wheelchairs from garage sales, or receive them as gifts from well-meaning friends. Unfortunately, this can lead to a poor "fit" between the user and the wheelchair, which can lead to skin problems in the future. To avoid this, it is very important to consult with an expert, such as a physical or occupational therapist, before selecting a wheelchair. People often use wheelchairs for many years and for extended periods a day, so it is important that the wheelchair be comfortable.

Power or electric wheelchairs are powered by batteries and require much less physical strength to move than standard (manual) chairs. They provide independence for people who are unable to propel themselves in manual chairs. Since these wheelchairs have to carry heavy batteries and power systems, the frames are generally sturdier than manual chair frames. Because of extra equipment, power chairs may be a bit wider, are harder to maneuver in tight spaces, and are very heavy and do not fold. Most power chairs will require a van for transportation. The wheelchair supplier should explain how and when to charge the batteries. With regular use, a battery should last a minimum of one year before replacement may be necessary. As wheelchair batteries differ from car batteries, buy the batteries only from a wheelchair supplier.

Scooters are also powered by batteries and resemble a horizontal platform with three wheels and a chair. Scooters are useful for people who can walk short distances but need help for long distances. Some scooters disassemble easily for transportation in the trunk of a vehicle. When selecting a scooter, check if you can lift the largest, heaviest part when disassembled. This may help determine how transportable it is for you.

PRINCIPLES OF CAREGIVING DEVELOPMENTAL DISABILITIES MODULE

CHAPTER 8: POSITIVE BEHAVIOR SUPPORT

FACILITATOR GUIDE

CONTENT:

- A. Understanding Behavior
- B. The Role of the Direct Care Worker in Positively Supporting Behavior
- C. Techniques for Effective Support

Estimated time for this chapter: 2.5 hours

Needed Materials:

1. Facilitator Guide
2. Participant Guides

COMPETENCIES:

(TO KNOW OR BE ABLE TO:)

1. Identify reasons why behaviors may occur.
2. Identify ways for the Direct Care Worker to get to know the person he/she works with and what works for the person to support success.
3. Identify what things a Direct Care Worker can do to support positive behavior and avoid problems.
4. Identify what things a Direct Care Worker can do when a conflict arises.
5. Describe and/or role-play redirection to avoid a power struggle.

KEY TERMS:

Behavior

Positive Behavior Support

Observable

Redirection

A. UNDERSTANDING BEHAVIOR

Facilitator Note:

Introduce the topic of Positive Behavior Support by stating that it is simply a philosophy or an approach to helping people improve behavioral challenges they may be experiencing. It is a way to help a person overcome habits or patterns of behavior that are preventing them from achieving their goals, or that are dangerous to them or someone else. The first step in understanding Positive Behavior Support is understanding behavior.

What is behavior?

Behavior is action. It is what someone does.

Facilitator Note:

Activity:

Facilitator asks: What is behavior? and records or repeats answers (most will correctly respond that it is action or what someone does). Then facilitator asks, "Is anger a behavior?" Some will respond "yes," some will respond "no." Facilitator will then ask those who responded "no," "What is anger?" Responses should be "emotion" or "feelings." Validate, anger is an emotion. It may be a possible *reason* for behavior, but it is not an action or behavior. Actions can be seen or heard or in some other way measured. Emotions cannot as they can be hidden and unobserved.

Activity:

Ask the participants to brainstorm with the person next to them some characteristics of behavior. There is a place in their packet to write down answers. After giving the group 1-2 minutes, ask them to call out what they came up with. Write their responses on a whiteboard or newsprint pad. Summarize the key points listed below. These are also included in the participant guide.

Notes:

Characteristics of Behavior:

- Behavior is an **action**.
- Behavior can be measured or counted.
- Behavior has a beginning and an end.
- Behavior has a reason, a purpose and/or a meaning.
- Behavior communicates something.

Behavior means we are alive, engaged and participating in our lives!
Behavior helps us to survive!
Behavior helps us enjoy life!
Behavior helps us get our needs met!
Behavior helps us to communicate!

People are constantly exhibiting behaviors. The only time when people are not engaging in behavior is after they have died.

How does behavior work?

We use behavior (or actions) to achieve a result. Examples:

- You may want the dishes washed. Possible behaviors:
 - You ask for help.
 - You complain that you have a lot to do.
 - You wash the dishes yourself.

- You want to see the ball game on TV, not the movie another person is watching. Possible behaviors:
 - You simply change the channel without asking.
 - You scream.
 - You ask the other person if they mind if you change the channel.
 - You talk to the other person about the ball game to get them interested in watching it.
 - You stand in front of the other person who now cannot see the TV.

Some behaviors are effective, others are not. Some behaviors are more acceptable than others.

When a behavior gets results, the person will repeat the behavior. This is true for all people, including the people we support.

Facilitator Note:

State that sometimes behavior is very effective. For example, if I ask you to stand up, and you stand up, my behavior of asking was effective in getting me what I wanted (you to stand up). If I ask you to stand up and you refuse, my behavior was not effective, and I may try other strategies like:

- Yelling at you to stand up.
- Pushing you out of the chair.
- Offering you a reward if you stand up.
- Explaining to you why I want you to stand up.

This is true also of the people we support. If I am working with someone and they are trying to get my attention by talking to me, showing me personal items, or otherwise trying to engage me, and I am not paying attention to them, they will learn quickly that these are not effective strategies. They may try other things like, screaming, pulling hair, or hitting. They will probably discover that these strategies are very effective in getting a support provider's attention.

In this way, sometimes the individuals that we support, and indeed, many typical people, have developed a habit of using strategies that are not really socially acceptable or positive, but that they have found are effective in getting their needs and/or wants met.

People use behaviors because they work for them under the circumstances.

Facilitator Note:

Activity:

Facilitator asks, "Everyone raise your hand who has someone in your life who has a habit that you find annoying and would want them to change?" (pause) "How many of those people have changed their habit simply because you wanted them to?" (pause) Most people will tend to shake their heads or respond in the negative for this question.

Ask: "OK, how many of you have habits that others have wanted you to change?" (pause) "How many of you have not changed your habit simply because others wanted you to change?" Most participant groups will respond in a mixed way to this question; you can acknowledge that some responded yes and others not.

If it is true for you and others, is it also true for the people that we serve?

People change behavior in order to make things work better for them, more effective, easier not because others want us to change.

Why does behavior happen?

Facilitator Note:

All behavior has a reason. To truly understand behavior, and to best support the person, we need to understand the reasons for behavior. Most behavior has multiple reasons. Because behavior has reasons, it communicates something about the person, if we understand the reasons for behavior we then better understand the person.

General reasons for behavior can include:

- **Something is wanted or needed.** For example, the person may be bored and want your attention. They may try to engage you in conversation or try to get you to pay attention to them through positive actions (performing desired tasks, making jokes, etc.). They may have learned that a very quick and effective way to get someone's attention is to behave in less positive ways, yelling, throwing things, trying to hit, etc.
- **Trying to escape from or avoid something.** For example, if a person doesn't want to do an assigned task they may begin to whine, complain, or refuse to perform the task.
- **For entertainment and sensory input.** This is especially true for people with sensory processing disorder and some people with autism. The behaviors of picking at their skin, hitting their head, spinning, or flapping their hands can be soothing when they are stressed, and can also provide sensory stimulation when they are bored.
- **To express intense feelings** including joy, fear, anger, sadness; and to relieve stress. These expressions can range from smiling and laughing to crying, screaming, throwing things, or hitting.
- **Biological, bio-chemical, or developmental processes/issues.** For example, if people are hungry, they will eat. If their heads hurt, they may hold it in their hands or hit it on the wall. If their hormones are in transition they may behave unpredictably, or be easily agitated. Medical and biological issues can include medication side effects, hunger, nausea, constipation, tiredness, fatigue, illness, pain, allergies, or blood sugar level.
- **To communicate.** For example, if people are hungry and not able to get their own food, the person may grab, point, moan, and touch their face or stomach. They may act out in a way completely unrelated to food if they don't have the expressive skills to tell you what they need. A person may take other people's food or attempt to hide food if getting food when he or she is hungry has been an issue in the past.

We cannot know the specific reasons for behavior for anyone until we get to know the person over a period of time. According to the Institute for Human Development at Northern Arizona University there are three things we must keep in mind when thinking about why someone is displaying a behavior.

1. All behavior that persists serves some purpose.
2. Every person is unique.
3. The best way to help someone change their behavior is to first understand the reasons behind the behavior.

B. THE ROLE OF THE DIRECT CARE WORKER IN POSITIVELY SUPPORTING BEHAVIOR

The role of the Direct Care Worker is to support positive helpful behaviors and to help prevent difficult challenging behavior

Positive Behavior Support (PBS) is an approach to helping people change behavior in a positive way that is based on four things:

- A. An **understanding** that people (even caregivers) do not control others, but seek to support others in their own behavior change process.
- B. A **belief** that there is a reason behind most difficult behavior, that people with difficult behavior should be treated with compassion and respect, and that they are entitled to lives of quality as well as effective services.
- C. The **application** of a large and growing body of knowledge about how to better understand people and make humane changes in their lives that can reduce the occurrence of difficult behavior.
- D. A **conviction** to continually move away from the threat and/or use of unpleasant events to manage behavior.

(This definition is taken from Article 9 training curriculum and is derived from the Positive Behavior Support Project, a collaboration between the Institute for Human Development at Northern Arizona University, University Affiliated Program and the Division of Developmental Disabilities.)

For you as a direct care worker to practice positive behavior support, you must get to know the person and how best to support them. People are going to be more willing to share, problem-solve and work with you if they feel they are understood and if they believe their opinions/beliefs are respected and validated. This approach is true whether a person can talk or not.

As a direct care worker, you want to assure the person has a chance to maintain their dignity and self respect regardless of the behavior or circumstances. Assisting a person to learn from their challenges and experiences can help them find the most effective and acceptable ways to meet their needs.

C. TECHNIQUES FOR EFFECTIVE SUPPORT

How can Direct Care Workers support positive helpful behaviors and prevent unhelpful challenging behaviors?

Possible activity:

Facilitator may have participants brainstorm the various ways that providers can get to know a person and get to know about them. The facilitator would then follow up that activity with the list below and elaborate on the items brainstormed.

Get to know the person:

- Observe.
- “Listen” to the person (not just with ears, but also with eyes, attention).
- Listen to others who know the person well.
- Review the documentation (the paperwork).
 - The planning document (Individual Service Plan (ISP), Person Centered Plan (PCP), etc.
 - Evaluations from professionals (Psychological, Physical Therapy, Occupational Therapy, Speech Therapy, Physical Exams, Hearing Screenings, etc.).
 - Any behavioral guidelines, analyses, or programs.
- Plan for Success.
 - Listening. Truly focus on the person, watch, listen, try to see the world through their eyes and acknowledge that you are there to support them.
 - Routine. Know, respect and implement their routine; if there is no routine assist the person in establishing a routine and let the routine become the framework for structure and activity.
 - Assure that the person has as much choice and control as possible. Even if an activity may be necessary, a person can have choices around when it happens, where it happens, with what it happens, how it happens.

Facilitator Note:

Provide an example here, such as showering. The person can choose if it happens before or after another event, if it is a shower or bath, if they use the green or the yellow towel, if they use the bar soap or bath gel, etc.

- Avoid saying “no” to the person and tolerate the person saying “no” to you. “No” is often a trigger for problems, because it leaves no room for choice, negotiation or alternatives. Direct Care Workers should avoid the use of the word as much as possible. Direct Care Workers should also respect and tolerate “No” from the person being supported. They have a legitimate right to say “No” and in some cases it is the only way that individuals can protect themselves and assert their rights.

Facilitator Note:

Possible activity: Emphasize that “no” can be communicated in a variety of ways other than speech. Have participants each identify one non-verbal way that a person can “say no.” Answers can include using sign language, shaking of the head, moving away, looking away, stiffening of the muscles, pushing someone else away, yelling, etc.

- **Model the best.** Teach appropriate and effective skills and behavior. Respond to challenges in the day and circumstances yourself in the best way possible. Do not set a standard for the person that you yourself do not follow. Demonstrate calm, control, problem solving, respect and consideration. Show the person what to do through your own behavior, not just your words.
- **Anticipate possible problems and avoid them.** Know the triggers for challenges and difficulties, avoid them where possible and if not possible, plan for the challenge and do problem solving in advance. Know the signs that the person is feeling stressed, anxious, angry, or fearful. As soon as those signs are evident, address them in positive ways to resolve the issue or cope with the problem.
- **Praise and reward the person.** Praise and reward the person when they display effective and appropriate behavior.
- Use redirection
 - Sometimes a person will focus on the same issue repeatedly, or will have certain triggers that upset them. At these and other times, it may be best to simply “get their mind off of it” and redirect them to something else. For example, if a person is afraid of dogs, and during a walk the individual notices a dog on the other side of the street, the direct care worker may want to redirect to something else of interest (while still avoiding the dog) like a bird, an interesting view, or a discussion of a past or future event that is of interest to the person.
 - Often, it is appropriate to validate what the person is expressing or experiencing before attempting to redirect them. For example, if a person wanted to watch a particular show on TV, but it’s not on, the direct care worker might say something like, “I know you must be disappointed that your show is not on. Would you like to play a game instead?”

Facilitator Note:

Review the SKILL: Redirecting a person, and practice in the classroom as needed. The skill is described on the following pages.

- When conflict occurs
 - **Avoid power struggles.** Work for both people “winning,” both getting at least a part of what is wanted/needed. Take a “both/and” approach, not either/or. Do not take the conflict personally. Remember you are not there to dictate or enforce rules, but to support and assist. The person should never perceive that

they are being punished by you. The person should be allowed and encouraged to arrive at his/her own acceptable solution. This means that choices and control are given to the individual supported.

- **Do something unexpected** (Novel stimuli). Responding in a unique and unexpected way to the conflict. This can sidestep the conflict for the moment, give both parties an opportunity to pause, reconsider and rebuild the collaborative relationship and may include laughter.
- **Evaluate, prioritize, and stick to basics.** Ask yourself, What is the essential here? Can this be done another way? What is the routine? Will this help build the relationship? Does it have to be done now? Does it have to be done this way? Keep just to the essentials and do not worry about the rest.
- **Offer opportunities for reconnection, reconciliation, learning and dignity.** After a conflict has occurred, use the time after to teach and learn different skills that are more acceptable. Encourage and support reconnection to self, the routine, to others; allow for and support reconciliation, dignity and self esteem.



Procedure: Redirecting a person

Overview

People sometimes get anxious and obsessive about events or things they want. They may have a particular interest that they can become obsessive about, or certain things that they fear, or that bring up other negative emotions. The redirection technique can be used to divert people's attention away from the stressful event to something that is more pleasant.

Behavioral problems can be greatly influenced by the reaction of the DCW to the situation. This skill will give the DCW techniques to de-escalate the situation.

Description of Procedure:

1. Use a calm, soothing voice.
2. If the individual does not mind being touched, gentle touch may be a powerful tool in conveying a caring attitude.
3. Use short, simple sentences.
4. Do not argue about statements the person makes. Arguing can escalate the situation. The Direct Care Worker should simply listen and validate that they understand what is being communicated (use active listening).
5. Respect the person's feelings (don't tell them they are wrong, or they are being silly, etc.). Often, a person being supported relies on non-verbal cues and he/she can tell if the caregiver is being patronizing or treating them like a child.

6. Try providing an alternative activity. Rely on your knowledge of the individual's interests and preferences for what to redirect them to.

Practical Tips:

- The DCW should redirect to an alternative activity, something the individual would enjoy.
- The alternative activity should take the functional ability of the individual into consideration.

Don't forget!

- Do not show frustration – use a calm, soothing approach.
- The alternative activity should be of interest to the individual – even if it's not of interest to the Direct Care Worker.

Practice Scenarios:

1. Mr. Allen is afraid of storms. Every afternoon during monsoon season he stares out the window watching the clouds. This can cause him to become very agitated, even if there are no storm clouds.
2. Mrs. Smith wants to go to the store right now. Due to circumstances outside of your control, you cannot take her to the store for another hour.

APPENDIX

Arizona Education Requirements for Direct Care Workers

Direct care workers (DCWs) must meet training and testing requirements if they work for agencies that provide services for publicly funded programs in Arizona.

This training requirement applies to these services provided in a person's home:

- Attendant care
- Personal care
- Housekeeping / homemaker

It applies to programs offered by these agencies:

- Arizona Health Care Cost Containment System (AHCCCS), Arizona Long Term Care Services (ALTCSS)
- Arizona Department of Economic Security (DES), Division of Developmental Disabilities (DDD)
- Arizona Department of Economic Security (DES), Division of Aging and Adult Services (DAAS), and its programs offered by the Area Agencies on Aging (AAA).

Note: There are different training requirements for caregivers in assisted living facilities. Please contact the Board of Examiners of Nursing Care Institution Administrators and Assisted Living Facility Managers www.aznciboard.us for more information.

Education standards and requirements include:

- Obtain certification in cardio-pulmonary resuscitation (CPR) and first aid.
- Demonstrate skills, knowledge and ability *prior* to providing care as a paid caregiver:
 - Pass required knowledge tests.
 - Demonstrate skills.
- Training and testing is based on the Arizona Direct Care Worker Competencies.
- A DCW may be exempted from the initial training and testing process if the DCW meets one of the following:
 - A DCW with an initial hire date prior to October 1, 2011 is deemed to meet the training and testing requirements with the DCW agency where they are currently employed. If the DCW becomes employed with another agency on or after October 1, 2011, he or she will have to complete the competency testing.

Appendix

- A caregiver who is a registered nurse (RN), licensed practical nurse (LPN), or certified nursing assistant (CNA) is exempt from the DCW training and testing requirements. This exemption allows the DCW agency the discretion to test and train their employees as desired.
- A DCW who has not worked as a DCW or has not had work experiences similar to that performed by DCWs in the last two years will be required to demonstrate competency by passing both a knowledge and skills test prior to providing services.
- DCWs with prior experience may take a *challenge exam*. If they pass, no additional training is required at that level. The challenge exam may be taken only one time.
- In order to offer the Arizona Standardized DCW Test, an organization must be an *approved training program*. This can include agencies that hire DCWs and provide services, community colleges, and private vocational programs.

ARIZONA DIRECT CARE WORKER COMPETENCIES (KNOWLEDGE AND SKILLS)

Developmental Disabilities (Level 2)

Topics

- A. Working with People with Developmental Disabilities
- B. Knowledge of Developmental Disabilities
- C. Abuse and Neglect
- D. Role and Requirements of the Division of Developmental Disabilities
- E. Support Plans
- F. Daily Living
- G. Incident Reporting
- H. Positive Behavior Supports

Skills

Skills are to be described and demonstrated (simulation), including these ancillary skills:

- § Communication skills, such as person-first language
 - § Promoting independence and self-determination / choice
 - § Enhancing dignity and respect
 - § Avoiding confrontations
-
- 1. Redirecting and/or avoiding a power struggle
 - 2. Assistance with dressing
 - 3. Assistance with meals
 - a. Total assistance (feeding)
 - b. Prompting, hand-over-hand assistance
 - 4. Assistance with brushing teeth
 - 5. Application and use of gait belt
 - 6. Assistance with ambulation (with/without assistive devices)
 - 7. Techniques for positioning a person in bed
 - 8. Techniques for positioning a person in a chair / wheelchair
 - 9. Transferring out of bed
 - 10. Transfer in and out of a wheelchair (with/without assistive devices)
 - 11. Assistance with self-administration of medications

A. Working with People with Developmental Disabilities

1. Identify important rights of people with developmental disabilities.
2. Give examples of Person-First Language.
3. Identify ways to build a positive relationship with the person you work for.
4. Explain the meaning of “self determination.”
5. Give examples of self determination.
6. Describe how to maintain a professional relationship with the person you work for.

B. Knowledge of Disabilities

1. Identify what “developmental disability” means.
2. Identify four conditions to qualify for services from the Division of Developmental Disabilities.
3. Identify affects of Cerebral Palsy.
4. Identify affects of Cognitive Disability.
5. Identify affects of Autism.
6. Identify affects of Epilepsy.
7. Name factors that contribute to seizure activity.
8. Explain how to recognize when a person is having seizure activity.
9. Give examples of what to do when a person is having seizure activity.
10. Give examples of what not to do when a person is having a seizure.
11. Identify when to call 911 when a person is having a seizure.
12. Describe how to document and report seizure activity.
13. Examples of ways to support a person after seizure activity.
14. Identify how “sensory integration challenges” may affect a person.

C. Abuse and Neglect

1. Identify physical signs and symptoms of suspected abuse and/or neglect.
2. Identify behavioral signs and symptoms of suspected abuse and/or neglect.
3. Identify environmental signs that may be related to suspected abuse and/or neglect.
4. Identify what information is necessary for reporting suspected abuse and neglect.
5. Explain what you need to do if you suspect abuse or neglect.

D. Role and Requirements of the Division of Developmental Disabilities (DDD)

1. Identify documentation and reporting requirements for the Division of Developmental Disabilities.
2. List activities that are restricted by the Division of Developmental Disabilities for Direct Care Workers.
3. Explain why notification is critical when you are unable to report to work as scheduled.
4. Identify to whom notification is required when you are unable to report to work as scheduled.
5. Identify how soon that notification should occur when you are unable to report to work as scheduled.
6. Identify responsibilities of the Attendant Care Worker/Direct Care Worker (DCW).

E. Support Plans

1. Explain the purpose of the Individual Support Plan (ISP) or other planning documents.
2. Identify two ways a DCW is involved in the team approach in plan development.
3. Name three parts of the planning documents that help inform the DCW about the person receiving support.
4. Identify ways to determine the level of assistance a person needs with daily living skills.

F. Daily Living

1. Give examples of techniques that can be used to promote independence and respect a person's preferences (for example, at mealtimes).

Appendix

2. Identify resources to identify an individual's mealtime needs.
3. Identify characteristics of people at risk for choking.
4. Identify choking prevention measures a DCW can use during and after mealtime.
5. Give examples of techniques that can be used to preserve dignity and privacy while providing personal care.
6. List risk factors for skin breakdown.
7. Explain the importance of repositioning and list techniques for preventing skin damage and pressure ulcers.
8. Identify and describe common assistive devices, including gait belt, walkers and wheelchairs.
9. Explain the importance of proper transfer skills and the safe use of assistive devices.
10. Identify issues related to providing assistance with bathing and toileting.
11. Describe and role-play (simulate) techniques for positioning and transferring a person.
 - a. Use of gait belt
 - b. Assistance with ambulation (with/without assistive devices)
 - c. Techniques for positioning a person in bed
 - d. Techniques for positioning a person in a wheelchair
 - e. Transfer in and out of a wheelchair (with or without assistive devices)
 - f. Transfer out of bed
12. Identify the responsibility of the DCW regarding assistance with self-administration of medications.
13. Describe the DCW's documentation requirements for medication self-administration.
14. Describe and role-play (simulate) assistance with personal care.
 - a. Assistance with dressing
 - b. Assistance with meals.
 - i. Total assistance (feeding)
 - ii. Prompting, hand-over-hand assistance
 - c. Assistance with brushing teeth

G. Incident Reporting

1. Give examples of incidents that need to be reported.
2. Identify the steps a DCW must take when an incident occurs.
3. Identify who needs to be notified about an incident.
4. Identify time frames for reporting incidents.
5. Identify essential information to be documented in an incident report.

H. Positive Behavior Support

1. Identify reasons why behaviors may occur.
2. Identify ways for the DCW to get to know the person he/she works with and what works for the person to support success.
3. Identify what things a DCW can do to support positive behavior and avoid problems.
4. Identify what things a DCW can do when a conflict arises.
5. Describe and role-play redirection and/or avoiding a power struggle.

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