PRINCIPLES OF CAREGIVING
DEVELOPMENTAL DISABILITIES MODULE

CHAPTER 1:
KNOWLEDGE OF DEVELOPMENTAL DISABILITIES

CONTENT:

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

Cerebral Palsy

Cognitive Disability

Developmental Disability

Epilepsy

Seizure Activity

Sensory Integration Challenges

A. DEVELOPMENTAL DISABILITIES

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

Exercise: Which disabilities do you know?

For example: Down syndrome, blindness

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

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

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

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

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

Who do we support?

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

B. INTRODUCTION TO HUMAN DEVELOPMENT

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

Social	Physical
Speech / language	Cognitive
Self-help	Emotional

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

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

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

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

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

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

C. THE FOUR DEVELOPMENTAL DISABILITIES

1. Autism

… affects social and communication abilities.

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

Characteristics of autism

Social interaction

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

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

Communication

Problems with verbal and nonverbal communication may include:

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

Limited or unusual activities and interests

People with autism may:

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

Unusual response to sensory stimuli (things experienced through the senses; sounds, textures, pressures, smells, sights, lights, etc.)
Unusual sensitivities may contribute to behavioral symptoms such as resistance to being touched and may also contribute to:

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

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

2. Cerebral Palsy

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

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

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

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

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

3. Cognitive disability

… affects how a person learns

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

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

4. Epilepsy (seizures)

… affects electrical / chemical impulses in the brain

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

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

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

D. RESPONDING TO SEIZURE ACTIVITY

Recognizing a Seizure

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

Responding to Seizures

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

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

For convulsive type seizures:
(convulsive means there is uncontrollable movement of the muscles)

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

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

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

What not to do during a seizure

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

When to call 911

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

Repeated Seizures can be life-threatening!
CALL 911!

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

Supporting a person after a seizure

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

After a seizure

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

- Note the time the seizure started and ended.

- Note the characteristics of the seizure.
    - Did the person lose consciousness?
    - Were they incontinent?
    - Did they experience convulsions?
    - What body parts were involved?
    - Was there a change in the coloring of the skin, or a blue tint to the lips or nail-beds?
    - What was the individual's condition following the seizure, i.e. were they confused, did they have a headache, were they aware of their environment?

- When it is safe to do so, write a seizure report and/or incident report following your agency's policy.

- After a seizure, a person is often very tired. Assist them as necessary to a place where they can rest.

Factors that may contribute to a seizure

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

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

E. SENSORY INTEGRATION CHALLENGES

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

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

Signs of sensory integration challenges MAY include:

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

F. GENERAL GUIDELINES FOR WORKING WITH PEOPLE WITH DEVELOPMENTAL DISABILITIES

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

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

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

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

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

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

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

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

PRINCIPLES OF CAREGIVING DEVELOPMENTAL DISABILITIES MODULE

CHAPTER 2 - WORKING WITH PEOPLE WITH DEVELOPMENTAL DISABILITIES

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

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 1st 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

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

A person-centered approach to support involves:

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

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:

- 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.

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

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

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 though 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 <u>him</u> 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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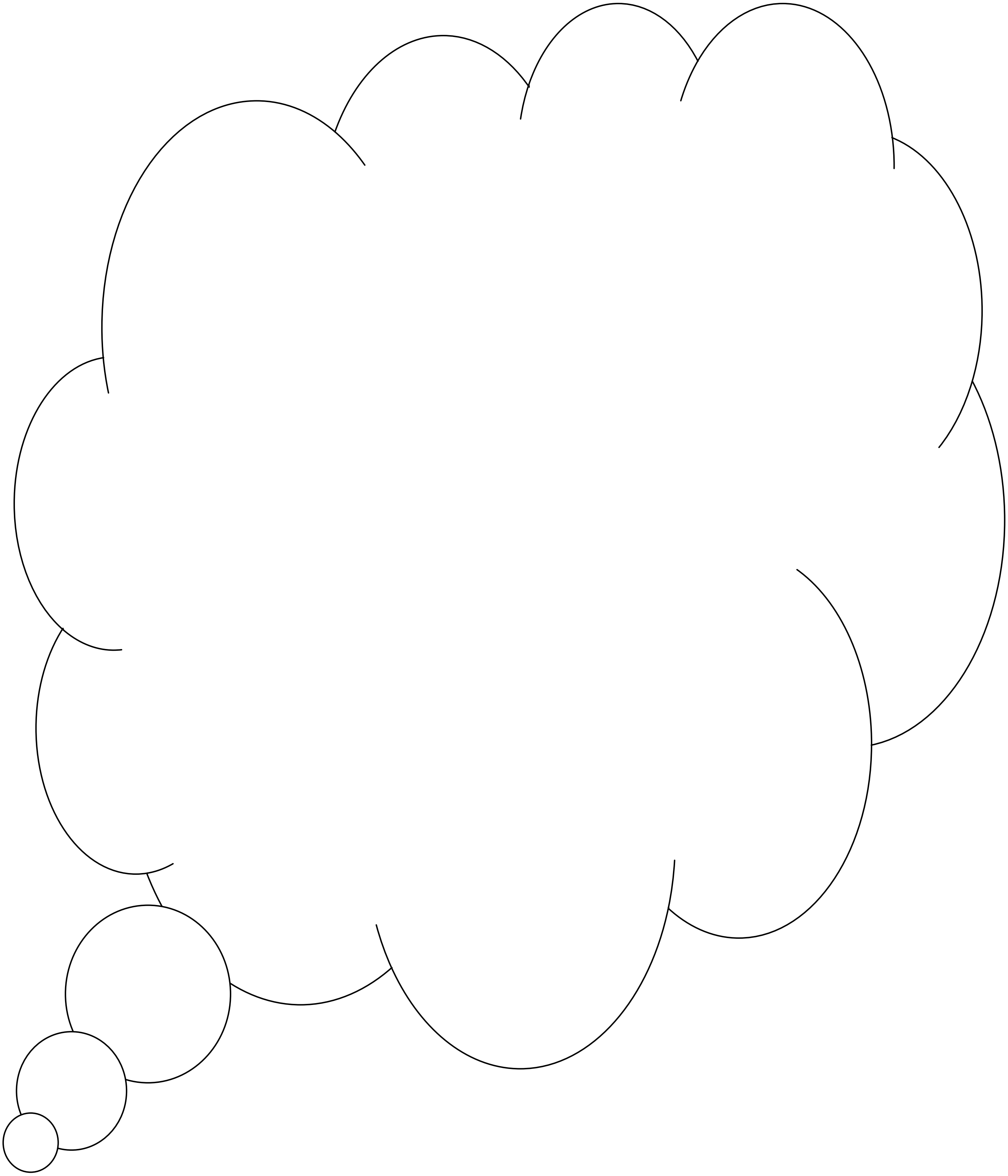
F. POSITIVE RELATIONSHIPS

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.

DEVEOPING POSITIVE RELATIONSHIPS – BRAINSTORMING



G. PROFESSIONAL RELATIONSHIPS

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.

PRINCIPLES OF CAREGIVING DEVELOPMENTAL DISABILITIES MODULE

CHAPTER 3:

ROLE AND REQUIREMENTS OF THE DIVISION OF DEVELOPMENTAL DISABILITIES

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

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

Attendant Care Agreement

Confidentiality

DDD – Division of Developmental Disabilities

DES – Department of Economic Security

Documentation

Reporting

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).

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.

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 encoring 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.

C. DOCUMENTATION AND REPORTING REQUIREMENTS

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

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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.

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 or 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

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

CONTENT:

A. Goal Planning

B. Individual Support Plans

C. Support Plan Basics

D. Roles and Responsibilities of Team Members

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
- Individual Support Plan (ISP)
- Long Term goal
- Risk assessment
- Short term goal
- Team assessment

A. GOAL PLANNING

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:

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

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.

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 is 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.

PRINCIPLES OF CAREGIVING
DEVELOPMENTAL DISABILITIES MODULE

CHAPTER 5:
ABUSE AND NEGLECT

CONTENT:

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

Abusive treatment

Adult Protective Services (APS)

Child Protective Services (CPS)

Exploitation

Mandatory reporting

Neglect

Vulnerable

A. INTRODUCTION

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

Reprinted from "Responding to Maltreatment of Children with Disabilities," Mary A. Steinberg, M.D. and Judith R. Hylton.

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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.

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.

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.

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.

D. RESPONDING TO ABUSE AND NEGLECT

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

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.

<table>
<tr><th colspan="2">What to Report</th></tr>
<tr><th>Abuse or Neglect of a Child</th><th>Abuse or Neglect of a Vulnerable Adult</th></tr>
<tr><td>Name of the child</td><td>Name of the adult</td></tr>
<tr><td>Address of the child</td><td>Name of responsible person – if it is someone other than the individual</td></tr>
<tr><td>Name of parents or the responsible person</td><td>Adults age</td></tr>
<tr><td>Age of the child</td><td>Nature and extent of their vulnerability</td></tr>
<tr><td>Nature and extent of injuries or neglect</td><td>Nature and extent of injuries, neglect or exploitation</td></tr>
<tr><td>Any evidence of previous injuries or neglect</td><td>Other information that may be helpful in investigating the case</td></tr>
<tr><td>Any other information that may be helpful in investigating the case</td><td>Other information as requested</td></tr>
<tr><td>Other information as requested</td><td></td></tr>
<tr><th colspan="2">When to Report</th></tr>
<tr><td colspan="2">Any time you are concerned for the immediate health and safety of the individual you are supporting, call law enforcement!</td></tr>
<tr><td>IMMEDIATELY report to a local Child Protective Services Worker</td><td>IMMEDIATELY report to a local adult protective services worker.</td></tr>
<tr><td>Submit written report (serious incident report) to the Division of Developmental Disabilities within one working day.</td><td>Submit written report (serious incident report) to the Division of Developmental Disabilities within one working day.</td></tr>
</table>

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.

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Report it verbally to your supervisor.

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Write an Incident Report.

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Participate in the investigation process as requested.

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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 sgns 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
- Los 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

PRINCIPLES OF CAREGIVING
DEVELOPMENTAL DISABILITIES MODULE

CHAPTER 6:
INCIDENT REPORTING

CONTENT:

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
Incident
Incident report
Serious incident
Verbal 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.

DISCUSSION POINT: What is an incident?

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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.

B. INCIDENT REPORTING

1. Basics: The purpose of incident reporting

- 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.

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 <u>verbal</u> and <u>written</u> 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.

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.

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.

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.

PRINCIPLES OF CAREGIVING DEVELOPMENTAL DISABILITIES MODULE

CHAPTER 7: DAILY LIVING

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

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)
Ambulation
Assistive device
Choking
Contracture
Gait belt
Grab bar

Incontinence
Pressure sore (ulcer)
Range of motion exercises
Skin integrity
Transfer, transferring
Walker
Wheelchair

A. INTRODUCTION

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.

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.

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.

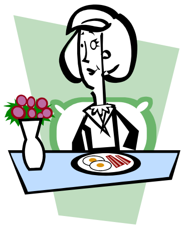
1. Assisting with setting up a meal

- 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:
  - Soft-cooked eggs, mashed potatoes and creamed cereals
  - 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
Tossed Salad
Chicken on bone
Popcorn
Bagels
Raisins

Marshmallows
Meat Chunks
Corn Chips
Hard Beans
Grapes
Canned Fruit

Hard Candy
Raw Apple
Pretzels
Thick Chewy Bread
Raw Carrots
Celery

Potato Chips
Chewing Gum
Nuts (all types)
Tortilla Chips
Caramel
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:
  - Having no teeth.
  - Having only a few teeth or a tooth ache, which may cause someone to not chew his or her food properly.
  - Dentures can make it difficult to sense whether food is fully chewed before it is swallowed.
  - 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!

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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.

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

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

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 <u>bony prominences</u>:

- 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.

What you need to look for and report:

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

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.

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.

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.

! **Remember to wear gloves when assisting a person with using the restroom and ostomy care. Wash hands before and after removal of the gloves.**

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/uoa_colostomy_en.pdf.)

H. TRANSFERRING

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.

!

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

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

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

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.

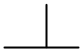
Description of procedure

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



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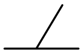

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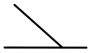

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Procedure: Positioning in wheelchair

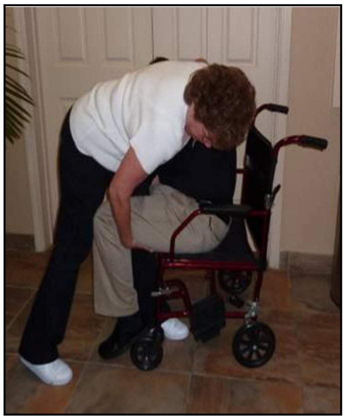
When a person with a disability is sitting in a wheelchair, make sure she/he is sitting upright to prevent the risk of pressure sores. A proper sitting position places the person in good, comfortable alignment. Good alignment involves head, shoulders, hips squarely over the axle of the wheel.

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 re-positioned.
- 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.

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.

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.

PRINCIPLES OF CAREGIVING
DEVELOPMENTAL DISABILITIES MODULE

CHAPTER 8:
POSITIVE BEHAVIOR SUPPORT

CONTENT:

A. Understanding Behavior

B. The Role of the Direct Care Worker in Positively Supporting Behavior

C. Techniques for Effective Support

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
Observable

Positive Behavior Support
Redirection

A. UNDERSTANDING BEHAVIOR

What is behavior?

Behavior is action. It is what someone does.

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.

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?

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?

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.
    - 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.
  - **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?"

- 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.