

# **CAREGIVING FUNDAMENTALS**

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

THE ARIZONA DIRECT CARE CURRICULUM PROJECT.

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

Please cite "Principles of Caregiving – Arizona Direct Care Curriculum Project" when using excerpts from this material. The title Principles of Caregiving should be used only with this material as approved by the Direct Care Workforce Committee. If changes are made to the content, the title Principles of Caregiving should not be used.

**Cover design and artwork** created by Gateway Community College, a Maricopa Community College. All rights to the logo and cover design are reserved by the Arizona Direct Care Curriculum Project for exclusive use with the *Principles of Caregiving* materials and classes.

For more information about the curriculum project, please visit the Arizona Direct Care Initiative website at <a href="https://www.azdirectcare.org">www.azdirectcare.org</a>.

#### PREFACE TO THE PRINCIPLES OF CAREGIVING

# The Development of Standardized Direct Care Professional Training in Arizona

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

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

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

i

#### **NOTES TO THE STUDENTS**

**Principles of Caregiving: Fundamentals** is the first part of the *Principles of Caregiving* series. It contains the material that is most likely needed by all direct care and direct support professionals. Additional training is available if you provide personal care or assistance with activities of daily living.

Fundamentals and any one of the modules listed below can be taken together in one class or they can be taken separately. Fundamentals should be completed first, and some review may be necessary before completing the additional module.

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

Principles of Caregiving includes the following modules:

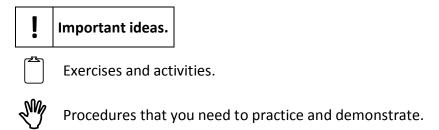
- Level 1: Fundamentals
- Level 2: Aging and Physical Disabilities
- Level 2: Developmental Disabilities
- Level 2: Alzheimer's Disease and Other Dementias

#### **Competencies for Arizona Direct Care Workers**

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

#### **Learning Objectives**

Each chapter of the *Caregiving Fundamentals* begins with an introductory page that lists the learning objectives and the key terms for that particular chapter. Some sections also list skills; these are procedures that you should practice and demonstrate to your instructor. The following symbols are used to identify certain components:



# PRINCIPLES OF CAREGIVING: FUNDAMENTALS

# **TABLE OF CONTENTS**

Ch	apter 1 — Overview 1-	-1
A.	Roles and Responsibilities of Direct Care Workers (DCWs)	-3
В.	Direct Care Services and Programs in Arizona 1-	.9
C.	Service Settings	.2
D.	Philosophy of Providing Direct Care and Supports 1-1	.3
Ε.	Resources 1-1	8.
Ch	apter 2 – Legal and Ethical Issues2-	-1
A.	Legal Terms and Definitions	3
В.	Distinction Between Law and Ethics	-3
C.	Avoiding Legal Action	4
D.	Ethical Principles	-4
Ε.	Client Rights	-5
F.	Direct Care Worker Rights 2-	-5
G.	Confidentiality (HIPAA)2-	6
Н.	Adult and Child Abuse	.0
l.	Advance Directives	.5
J.	Do Not Resuscitate ORDER (DNR), the Orange Form 2-1	.6
K.	Resources 2-1	.8
Ch	apter 3 — Communication 3-	-1
A.	Components of Effective Communication	-3
В.	Communication Styles	-5
C.	Attitude	-7
D.	Barriers to Communication 3-	-7
E.	Therapeutic Communication	.9
F.	Respectful Communication	.2
G.	Communicating with Individuals with Disabilities	.2
Н.	A Guide to Wheelchair Etiquette	.5
I.	People First Language	.6
J.	Resources 3-1	.8

#### **Table of Contents**

	napter 4 – Cultural Competency	
A.	Definitions	4-3
В.	Awareness of Cultural Differences	4-3
C.	Different Cultures in Arizona	4-6
D.	Cross-Cultural Communication	4-7
Ε.	Resources	4-11
Ch	napter 5 – Job Management Skills	5-1
A.		
В.	Time Management and Organization	5-9
C.	Boundaries	5-12
D.	Principles of Body Mechanics	5-14
E.	Safety Tips for the DCW	5-18
F.	Resources	5-19
Ch	napter 6 – Observing, Reporting and Documenting	6-1
	Purpose and Importance of Observing and Reporting	
В.	Observing and Monitoring	6-3
C.	Care Plans and Support Plans	6-7
D.	Reporting	6-7
E.	Documenting	6-7
Ch	napter 7 – Infection Control	7-1
	The Spread of Diseases and Prevention	
В.	Common Bloodborne Pathogens	7-4
C.	Other Common Conditions	7-8
D.	Policies and Guidelines	7-10
E.	Procedures	7-12
F.	Resources	7-20
Ch	napter 8 – Nutrition and Food Preparation	8-1
	Basic Nutrition	
В.	Menu Planning	8-5
C.	Food Safety	8-12
D.	Special Dietary Needs and Diets	8-15
E.	Menu and Shopping Tips	8-18

# **Table of Contents**

Ch	apter 9 – Fire, Safety and Emergency Procedures	9-1
A.	Emergency Planning	9-3
В.	Medical Emergencies	9-7
C.	Falls	9-9
D.	Fire Safety	9-12
E.	Activity: What Would You Do?	9-18
F.	Resources	9-19
Ch	apter 10 – Home Environment Maintenance	10-1
A.	Deciding What to Do	10-3
В.	Supplies	10-5
C.	Cleaning	10-5
D.	Laundry	10-7
E.	Bed Making	10-8
F.	Cultural and Religious Issues	10-9
G.	Activity: Planning and Prioritizing Chores	10-9

# PRINCIPLES OF CAREGIVING: FUNDAMENTALS

# **CHAPTER 1 - OVERVIEW**

#### **CONTENTS**

- A. Roles and Responsibilities of Direct Care Workers (DCWs)
  - 1. Definition
  - 2. Responsibilities
  - 3. Training and Orientation
- B. Direct Care Services and Programs in Arizona
  - 1. Definitions
  - 2. Public Programs
  - 3. Support Organizations
- C. Service Settings
- D. Philosophy of Providing Direct Care and Supports
  - 1. Basic Principles
  - 2. Independent Living and Self-Determination Statement
  - 3. Working with Older Adults
  - 4. History of Treatment of Individuals with Disabilities
  - 5. The Independent Living Movement Philosophy
- E. Resources

#### **OBJECTIVES**

- 1. Describe what direct care workers (DCWs) do and where they may work.
- 2. List five or more job titles used to differentiate various direct care worker functions.
- 3. Describe the continuum of care, service settings, and job opportunities for DCWs in various community settings.
- 4. Describe the philosophy, history, and benefits of the Independent Living Movement.
- 5. Define the term *scope of practice* and list three or more factors that determine the scope of practice for DCWs.

#### **KEY TERMS**

Activities of daily living (ADL) Direct care

Agency Direct care worker (DCW)

Assisted living facility Independent living movement

Care plan Scope of practice

Consumer-directed care Support plan

Continuum of care

# A. ROLES AND RESPONSIBILITES OF DIRECT CARE WORKERS (DCWS)

#### 1. Definition

A direct care worker (DCW) is a person who provides assistance or support with daily activities. This can include bathing and grooming, housekeeping, help with meals, and encouragement of behaviors that enhance community involvement. This training focuses on the skills, knowledge, and abilities that have been identified as critical.

#### Possible job titles for a Direct Care Worker

- Home care aide
- Personal care aide
- Direct support professional
- Attendant
- Personal care assistant
- Respite worker
- Companion
- Caregiver
- Care associate

? Can you think of any more titles?

#### 2. Responsibilities

#### **Job descriptions**

The list of things a DCW can and cannot do depends on the setting and the specific job. It is not possible to write one job description. These are some common tasks for DCWs:

- Personal care: helping a person in the bath, getting dressed, and with eating
- Running errands and shopping; taking a client to appointments
- Chores around the house: cleaning, meal preparation
- Help a person to become more self-sufficient; teach and encourage them to live the most independent lifestyle

In order to know job expectations and responsibilities, a DCW should attend agency orientation and in-services, and read the job descriptions. DCWs also need to become familiar with service plans, also called *care plans* and *support plans*. Such a plan is created for each client. It describes exactly what services should be provided. The fact that a DCW knows how to do a lot of things does not mean that the DCW will provide all these services to every person.



If you have questions about your job duties, contact the supervisor.

# 8003

# Independent Living is My Choice! - Thank you Attendant Care!

My association with the Personal Attendant Program began in March of 1986. I had just had hip replacement surgery at Good Samaritan Hospital. During my discharge planning session I was asked by the social worker what my plans were when I went home. I told her that I was going home temporarily, because at the time I was working with a social worker at Phoenix Indian Medical Center in locating a nursing home for me to move into. I wanted to live in a place where I would be able to receive proper physical care and where I could live until whenever. As a person with arthritis, this was very vital for me, as my arthritis pain was flaring up, causing me 24-7 pain. It was at my discharge plan meeting that I first heard of the Personal Attendant Program. The social worker said that I didn't have to live in a Skilled Nursing Facility (SNF) until whenever, she said, "There is a program in town that could help you live on your own, in your own place, and provide home care assistance to help you with your Activities of Daily Living (ADL)".

After staying at a nursing home for six months, I moved out and into my own apartment. I had a roommate who had Muscular Dystrophy (MD) who also was a power chair user. Our first attendant was a young man who had just finished taking the Personal Attendant Class and was looking for a live-in position. My life as a real independent person began.

My freedom depends on others, and because of my disability, always will. Coming from a small community in Arizona, I have no family living anywhere in the Valley. All my attendants have been non-family members/strangers who come into my life and become the most important part of my freedom/life.

My being able to do the things I do depends on the person who is my attendant at the time. At first just being able to live freely outside of a nursing home was a scary experience. There was always a fear of things going wrong. Will my attendant be late? Will he or she make it at all? Will I have enough money to pay my bills? There were many other fears, which are too many to mention.

I have been very lucky to have had attendants who I could depend on as well as trust. Without these people I wouldn't have accomplished in my life goals that I would have never fathomed, coming from where I came from. Without the Attendant Program I would have never been able to attend college, earn three degrees (AAA, BSW and an MSW), go where I have gone, and see what I have seen (NCIL in Washington D.C., three times), and have a full-time job.

Without my attendant being there for me day in and day out, dreams would only be dreams and not reality. It is hard to imagine what life would be like without my attendant. It is very difficult to think of having to live in a nursing home for the rest of my life. Thanks to this program, I am free. I am someone with a disability who came from a small Tohono O'odham Village. I am my own person who decides how to live my life day to day. I make my own choices in life, (what to have for breakfast, when to get up or go to bed, etc...) things others take for granted.

I often acknowledge and thank those who are willing to give of their time and of themselves in assisting individuals with disabilities to live freely, as freely as one can be.

Fernando C., recipient of attendant care



# Factors that influence the DCW's responsibilities Agency policies and procedures

Each agency has its own policies and procedures. What a DCW may do when working for one agency may not be the same for another agency. For example, what to do if a client falls.

#### Agency licenses and contracts

Agencies working with public programs have contracts. These describe what the agency must do for clients and what the DCWs can do. Some agencies have a license for certain services. For example, home health care agencies may require more training for their staff.

# Type of care settings

The scope of what a DCW will do is also based on the type of care setting. For example, a person's private home is different from an assisted living home.

#### The service team

For any person receiving support, a service team helps to coordinate the services. Each person on the team has certain functions. Each situation is different, but often the following are on the team:



- 1. Family members (spouse, parents, children)
  - a. Provide emotional support.
  - b. Encourage the person to do as much as possible for themselves for as long as possible to prevent atrophy of the mind and body.
  - c. Communicate with the case manager/support coordinator about changes in the person's needs.
- 2. Case manager/support coordinator
  - a. Determine the needs of the person and arrange for the needed services.
  - b. Monitor for changes in the person's needs.
- 3. Agency representative (agency supervisor, staffing coordinator)
  - a. Arrange compatible, reliable direct care workers for the needs of the consumer.
- 4. Direct care worker
  - a. Provide assistance with tasks listed in the service plan.
  - b. Report observations to supervisor.
- 5. Supervisor
  - a. Monitor the direct care worker's performance.
  - b. Answer guestions and direct the DCW in his/her role.

#### 6. Primary care physician

- a. Monitor and manage the physical health of the consumer.
- b. Communicate with the case manager/support coordinator about changes in the client's needs.

#### 7. Others (therapists, teachers, psychologist, etc.)

a. Communicate with the case manager/support coordinator about changes in the client's needs.

The DCW is an important member of the service team. As a DCW, you may spend more time with a client than others. When providing assistance in the person's home, observe any changes and problems. If you notice anything unusual—both positive and negative—report it to your supervisor.

# 3. Training and Orientation

#### a. General training and orientation

All DCWs need training that helps them to do their jobs well. This also means being safe and effective, and keeping the client safe. If you work for an agency, your employer may provide the training. Classes are also offered by some colleges and other training programs.

When a DCW is hired by an agency, he or she will attend the agency's orientation. This is required even if the DCW has completed this course. The orientation to the agency is much more specific to the particular organization. It includes policies, paperwork requirements, the agency's history, job expectations, etc.



#### b. Training requirement for public programs

Many agencies are providers for public programs. These are programs paid by the government, including the Arizona Long Term Care System (ALTCS) and the Department of Economic Security (DES). See Section B.2, Public Programs in Arizona, below.

Agencies that provide services for ALTCS and DES have specific requirements. This includes training and standardized tests. The appendix of this module lists the Arizona Direct Care Worker Competencies. This is the list of what DCWs must know or be able to do. They are also posted at <a href="https://www.azdirectcare.org">www.azdirectcare.org</a>. You cannot work for an ALTCS or DES provider agency until you have passed the tests. An exception is made for workers in the ALTCS Self-Directed Attendant Care Program.

#### **Initial training**

This is the training you complete before you start working.

- Level 1 (Fundamentals): Required of all direct care workers.
- Level 2 (one specialized module): Required for personal care and attendant care workers. An exception is family members, who will get person-specific training. Agencies can choose to require Level 2 training.

The *Principles of Caregiving* course includes all the material required for the training. The Fundamentals module is Level 1, and any one of the following modules can be used for Level 2:

- Aging and Physical Disabilities
- Developmental Disabilities
- Dementia and Alzheimer's Disease

Most direct care workers will take Fundamentals and at least one other module. Completing more than one module may create more opportunities for DCWs to work in a variety of settings.

#### **Continuing education**

Professional standards dictate the importance of continuing education. It helps you keep abreast of changes in the field. Ongoing training also helps improve the quality of care.

Each agency will offer continuing education. In agencies providing services for statefunded programs, DCWs must complete 6 hours of continuing education per year. Agencies with a behavioral health license must offer 24 hours per year.

#### c. DCW professional standards

In addition to training, a DCW needs high professional standards. Your behavior also affects your relationship with the client. The DCW and the client need respect for each other and a professional relationship. The persons for whom you provide services must be able to rely on you. Your services help keep people safe and independent.

Learn more about professionalism and boundaries in Chapter 5, Job Management Skills. Here is a list of important standards:

- Carry out responsibilities of the job the best way you can—take pride in a job well done.
- Get the training you need; get continuing education each year.
- Be dependable and reliable.
- Maintain a high standard of personal health, hygiene and appearance.
- Show respect for the client's privacy when you enter his/her home.
- Do not use the client's things for yourself (phone, food, medications, etc.).

- Recognize and respect the right of self-determination and lifestyle.
- Keep your professional life separate from your personal life.
- Control any negative reactions to chronic disability or living conditions.
- Maintain safe conditions in the work environment.
- Do not bring your family or friends to the client's home.



It is better to ask questions than do something that may be unsafe, cause disciplinary action, and/or a liability issue.

#### B. DIRECT CARE SERVICES AND PROGRAMS IN ARIZONA

#### 1. Definitions

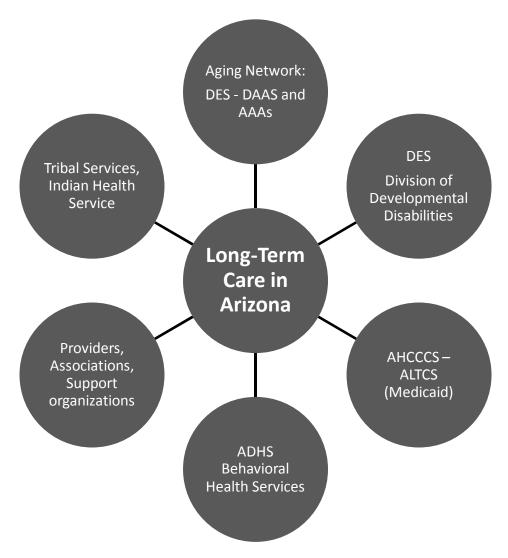
- Long-term care (LTC): Services for people who need support for a longer period of time. Examples: A person with a disability; an older person who cannot walk alone.
- Acute health care: Services for people who are suddenly ill or had an accident. Examples: seeing a doctor for the flu; going to the hospital after a heart attack.
- **Home and community based services (HCBS):** Many LTC services can be offered in a person's home or in assisted living. Most people are happier in their own homes.
- **Private pay:** Anyone can pay for direct care services privately. There are private duty nurses and private caregivers.
- **Public programs:** Programs paid by a government. These can be state, county, city, or federal government programs. Most of these programs are for people with low incomes.

# 2. Public Programs in Arizona

#### a. Government agencies

- Arizona Health Care Cost Containment System (AHCCCS) www.azahcccs.gov
  - Acute health care (Medicaid): medical services for low income persons.
  - Arizona Long Term Care System (ALTCS): care and support for low-income older adults and people with disabilities who need services for a long time.
- Arizona Department of Economic Security (DES) www.azdes.gov
  - Division of Aging and Adult Services (DAAS): assistance for low-income older adults and people with disabilities. Programs are provided through Area Agencies on Aging (AAA).
  - Division of Developmental Disabilities (DDD): information and support for children and adults with developmental disabilities.
- Arizona Department of Health Services (ADHS) www.azdhs.gov
  - Division of Licensing: licensing and inspection of assisted living facilities, nursing homes, clinics and hospitals.
  - Behavioral Health Services (BHS): Works with Regional Behavioral Health Authorities (RBHAs) to provide services for people with addiction or mental health challenges.

# **b.** The Arizona Network of Long Term Care Services



#### c. Who can get public services

- Older adults, over the age of 60, who are frail or vulnerable. This means they need help with daily activities, or they are at risk for injury and illness.
- **Persons with disabilities**. Examples are a person in a wheelchair after an accident or someone with a mental illness.
- Children and adults with a developmental disabilities. Examples are autism, cerebral palsy, epilepsy, and cognitive disabilities.

#### d. DCW services available in the home

- Personal Care: Assistance with routine personal activities. Helping people be as self-sufficient as possible. This can be eating, dressing, bathing, and moving about.
- Housekeeping/Homemaker: Assistance with chores in the home: cleaning, picking up things, laundry.
- Attendant Care: Includes personal care and housekeeping.
- Respite: Bringing a DCW to the home so that the family caregiver can take a break.

#### e. AZ Links – Arizona's Aging and Disability Resource Center

AZ Links is a special project to provide information and assistance to people in Arizona. Information is free on <a href="www.azlinks.gov">www.azlinks.gov</a>, and counseling on personal options is available through AZ Links sites.

# 3. Support Organizations

These organizations are often non-profit agencies, and many work with government agencies to offer information and assistance.

- Area Agencies on Aging (AAA): Information on long term care, home delivered meals, case management, and support for family caregivers. Arizona has eight AAAs.
- Centers for Independent Living (CIL): Information and resources for people with disabilities. The CILs also advocate for people with disabilities and help them become more independent.
- **Consumer organizations:** The Alzheimer's Association, Arizona Autism United, and the Arizona Spinal Cord Injury Association are some examples.

Did y	Did you know?					
1.	All DCWs in Arizona need the same training	True	False			
2.	All older adults in Arizona get public benefits.	True	False			
3.	A standardized test is required for DCWs in agencies that work for ALTCS and DES programs	True	False			
4.	Six hours of continuing education per year are required by these agencies	True	False			
5.	Most people prefer to live at home and get assistance there	True	False			

# **C. SERVICE SETTINGS**

This training is for DCWs who work in a person's home. There are other places where direct care is provided. More training may be needed, but the DCW training is a good foundation.

Service Settings	Work Environment
The <b>individual's home</b> (or a relative's home). The individual may also attend adult day services or school.	<ul><li>Staff works in the person's home</li><li>Staff usually works alone</li><li>Training: DCW training</li></ul>
A <b>group home</b> , usually for a specific group of disabilities, such as a group home for individuals with developmental disabilities	<ul> <li>Working in a home-like setting</li> <li>Limited number of co-workers</li> <li>Staff is responsible for assisting more than just one individual</li> <li>Training: DCW plus specialized training for group homes</li> </ul>
<ul> <li>An assisted living home</li> <li>Provides 24 hour care in a home-like setting for 1-10 residents</li> <li>May or may not be owner occupied</li> <li>An adult foster care home is owner occupied and cares for 1-4 residents</li> </ul>	<ul> <li>Similar to group home</li> <li>Working in a home-like setting</li> <li>Limited number of co-workers</li> <li>Staff is responsible for assisting more than just one person</li> <li>Up to 10 individuals and all are adults with various disabilities</li> <li>Training: DCW and/or Assisted Living Caregiver</li> </ul>
<ul> <li>An assisted living facility</li> <li>Individuals usually live in individual apartments and pay for the services they require</li> <li>Larger facilities, can be up to 100 or more units</li> <li>Often the larger facilities are divided into functional units depending on how much assistance the person needs</li> </ul>	<ul> <li>Usually care is provided in the individual's apartment</li> <li>Staff usually works alone in the individual's apartment but has co-workers working in the same complex</li> <li>Staff may work for one client or several depending on the needs of the person</li> <li>Clients may privately pay for staff assistance above and beyond the services offered by the facility. The staff would be working for the individual, not the facility</li> <li>Training: Assisted Living Caregiver</li> </ul>
<ul> <li>A dementia specific unit</li> <li>Similar to an assisted living facility but is specific to the care of persons who have dementia</li> <li>These units are usually locked so that persons cannot wander away</li> </ul>	<ul> <li>Staff works on the unit with other co-workers (number depends on how large the unit is)</li> <li>Staff assigned to assist more than one individual</li> <li>Training: DCW and/or Assisted Living Caregiver</li> </ul>
A <b>skilled nursing facility</b> (nursing home)  • Skilled nursing care 24/7	<ul> <li>Staff works with co-workers in the facility. The supervisor is a nurse. Training: Certified Nursing Assistant (CNA)</li> <li>There are also support positions (e.g., activities or dietary). Training: DCW and/or specialized training</li> </ul>

#### D. PHILOSOPHY OF PROVIDING DIRECT CARE AND SUPPORTS

#### 1. Basic Principles

There are basic principles—beliefs—that all people have rights, abilities, and freedom of choice. Arizona state agencies and the providers that helped write this curriculum support these principles.

- **Independence:** Freedom to direct one's life; able to do things for yourself when possible.
- **Choice:** Each person chooses what to do and when to do it; caregivers do not tell them what to do.
- **Dignity:** Each individual is a person; each person needs respect, privacy and is treated the way he or she wants to be treated. When people need assistance, they still need to feel they are valued and in control of their lives.
- **People can learn:** Some people may be slower, some need assistance, some have only a little energy. All can learn and change.
- **Person-centered approach:** Assistance or support is given when or how the person needs it. Examples: a person from another culture may prefer certain foods; some people want a lot of treatments, others want less help.
- **Consumer-direction:** When possible, the client tells the caregivers what to do, when and how. There are some public programs with *consumer direction*. This means that the person interviews, hires, trains, and supervises the DCW.

#### Care, Support, Assistance—Does it matter?

Many DCWs are *caregivers*—they provide care for another person. Family members and friends can be caregivers.

Some people need assistance, perhaps because they are in a wheelchair. They do not feel ill, they do not need to "be cared for." They just need help with some activities. These individuals may prefer to use the terms *assistance* or *in-home supports*. The DCW may be called a *personal care assistant* or an *attendant*.

Use the person-centered approach: find out what the person expects and wants.

#### 2. Independent Living and Self-Determination Statement

Independent living and self-determination are values that stress dignity, self-responsibility, choices and decision making. Independent living is the freedom to direct one's own life. Each individual has the right to optimize his or her personal ability and fully integrate into the community.

What does this mean? You get to be in charge of your own life. You might seek advice, but you make decisions for yourself. You know what is best for you. It does not mean

doing everything all by yourself. You might need assistance around your home. You choose who assists you. You pursue your dreams. You explore your potential, talents and abilities. It means having the freedom to fail and learn from your failures as well as experience successes, just as non-disabled people do. The opportunity for independent living and self-determination is essential to the well being of people with disabilities.

- We promote and value equal opportunity, full integration and consumer choice.
- We promote the achievement of full rights and empowerment of all persons with disabilities.
- We promote the full participation of people with disabilities in the cultural, social, recreational and economic life of the community.
- We promote consumer choice/control—the individual's right to make informed decisions regarding his or her best interests in all aspects of life.
- We promote the involvement of people with disabilities in the decision-making process of community programs and services.

# 3. Working with Older Adults

As people get older, they tend to slow down a little. Unfortunately, younger people sometimes show disrespect or simply become impatient. Ageism—or age discrimination—is all too common in our society: many products or movies are about and for younger people; we are always in a hurry and we see older adults as being too slow. If you work with older adults, it is important to have the right mindset. Keep in mind a few principles:

- Older adults can do a lot and learn new things. Like all people, they feel better when they can do things for themselves.
- Older people have experience and wisdom. They may not know everything you know, but they know a lot.
- Always treat an older adult as an adult. Adults are not like children.
- Older people have interests and likes and dislikes. They want to make their own choices.

# 4. History of Treatment of Individuals with Disabilities

#### **Ancient Times**

- People with disabilities were discarded.
- They may have been thought unworthy to feed.

#### Middle Ages

- People with disabilities were thought to be possessed by evil spirits.
- Disabilities were thought to be caused by sins of the parents.

#### 1700-1800s

- Schools were being formed.
- Braille was established.

#### 1900s

Institutions were established for "genetic mistakes."

#### 1930s

• Hitler was striving for the "Super Race" and proposed sterilizing people with hereditary disabilities so that they could not have children. Gas chambers were used to kill over two hundred thousand people with disabilities.

#### 1950s

- Television represented people with disabilities with a negative stereotype, creating "The Pity Soap Box."
- Support organizations were founded:
  - March of Dimes
  - Muscular Dystrophy Telethon

#### 1990s

- Americans with Disabilities Act (ADA) becomes law. Justin Dart is considered the father of the ADA, which had an impact on many aspects of life:
  - Access to public buildings
  - Telecommunications
  - Transportation
  - Job opportunities

# 5. The Independent Living Movement Philosophy

In the early 1960's a handful of students with disabilities at the University of California, Berkeley, decided they were tired of living in a hospital setting and being isolated from community activities. They felt that as human beings they had a right to choose their own lifestyle. After examining the risks and accepting the responsibilities, they moved into apartments in the community, arranged for assistant care, and won for themselves the freedom to choose. The freedom for individuals who experience a disability to make decision concerning their lives and being given the opportunity to develop fully according to their potential are essential elements in what has become known as "Independent Living."

With the passage of the 1978 amendments to the Rehabilitation Act of 1973, Congress recognized the value of Independent Living and allocated money to fund programs which assist persons who experience a disability in meeting their needs.

Independent Living became a reality in Arizona in 1977 when a group of residents who experience disabilities attended the White House Conference on Handicapped Individuals. They were introduced to the Independent Living concept and were inspired to return to Arizona to begin a legislative and advocacy group. They organized the Arizona Congress for Action, a private, non-profit affiliate of the American Coalition of Citizens with Disabilities (ACCD). Their ideal was to bring together representatives from various groups concerned with issues relating to individuals with disabilities in order to stimulate cross-disability communication, to increase awareness of difficulties faced by persons with disabilities, and to make the Independent Living concept a reality among the disabled population of Arizona.

Toward this end, federal funds were applied for and a proposal was written to establish an Independent Living Center. In 1980, federal funds were received and divided between the two larger urban areas of Arizona. In Tucson, the Metropolitan Independent Living Center (MILC) was established, and in Phoenix, Arizona Bridge to Independent Living (ABIL) became a reality.

Used with permission from *Personal Assistant Training Manual*, Arizona Bridge to Independent Living (ABIL)

#### Did you know?

- 1. Mrs. Brown is eating lunch. She wants cereal and a banana.
  - a. You help her with the cereal and banana.
  - b. You fix her a sandwich because that is a better lunch.
- 2. Mr. Jones needs to get dressed.
  - a. You show him several shirts and let him pick one.
  - b. You take a shirt from the closet and start putting it on him.
- 3. Mrs. Green often spills milk when she opens the carton.
  - a. You let her open the carton of milk.
  - b. You do it for her to avoid the mess.
- 4. Mrs. Miller tends to fall asleep in front of the TV.
  - a. You leave the TV on her program.
  - b. You change the channel to your favorite show.
- 5. Mr. Houston spilled coffee on his shirt.
  - a. You ask him if he wants to change.
  - b. You go to him and start to unbutton the shirt.
  - c. You tell him to change.
  - d. Nothing needs to be done.
- 6. John G. has a cognitive impairment. He wants to heat up soup, but he has problems with the stove.
  - a. You heat up soup for him.
  - b. You tell him to fix a sandwich.
  - c. You assist him with heating soup in the microwave.
- 7. Mrs. Lang just asked for the third time how to take photos with the cell phone.
  - a. You tell her it's too hard to learn.
  - b. You change the subject; she is too old to learn this.
  - c. You show her again.

#### E. RESOURCES

For more information about direct care workers, visit:

- Arizona Direct Care Workforce Initiative, www.azdirectcare.org
- Paraprofessional Healthcare Institute (PHI), www.paraprofessional.org/
- National Clearinghouse on the Direct Care Workforce, www.directcareclearinghouse.org
- Iowa Caregivers Association, <u>www.iowacaregivers.org</u>

For more information about assistance programs, visit

- AZ Links <u>www.azlinks.gov</u>
- Area Agencies on Aging
- Independent Living Centers
- Arizona Department of Economic Security, <u>www.azdes.gov</u>
- Arizona Department of Health Services, <u>www.azdhs.gov</u>
- Arizona Health Care Cost Containment System, www.azahcccs.gov