

Your Partner For A Stronger Arizona

Division of Aging and Adult Services 1789 West Jefferson Street / 950A Phoenix, AZ 85007 Phone: (602) 542-4446

# Arizona Case Management Handbook

Prepared by
The Case Management Handbook Committee
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#### 1. PART ONE: ADMINISTRATION OF SERVICES

#### 1.1. AGING AND LONG-TERM CARE SERVICES

Aging services have a specified organizational structure at the federal, state, and local level. This structure is established through the Older Americans Act of 1965, which authorizes and funds many of the home and community-based services. The aging network is also an important component of the state's long-term care system. Other programs, such as behavioral health and services for individuals with a developmental disability are part of long-term care, along with the state's Medicaid program. This chapter describes the aging network and the long-term care system, programs and services, funding streams, and initiatives to help coordinate services across programs.

## 1.1.1. THE OLDER AMERICANS ACT (OAA)1

The Older Americans Act (OAA) was signed into law in 1965 to meet the diverse needs of the growing number of older individuals in the United States. It was last amended in 2006. The OAA provides the foundation for encouraging, organizing, and coordinating the development or enhancement of comprehensive and coordinated community-based systems. The OAA has seven parts (titles):

#### **Title I: Declaration of Objectives and Definitions**

Introduces the purposes and goals on which the OAA's policies and programs are based. It provides a statement of our nation's commitment to assuring the well-being of older persons. Title I also includes definitions and the major objectives of the Act:

- 1. An adequate income in retirement.
- 2. The best possible physical and mental health -without regard to economic status.
- 3. Obtaining and maintaining suitable housing available at costs older citizens can afford.
- 4. Full restorative services for those who require institutional care, and a comprehensive array of community-based long-term care services including support to family members.
- 5. Opportunity for employment.
- 6. Retirement in health, honor, dignity.
- 7. Participating in and contributing to meaningful activity.
- 8. Efficient community services which provide choice with emphasis on maintaining a continuum of care.
- 9. Immediate benefit from proven research knowledge, which can sustain and improve health and happiness.
- 10. Freedom, independence, and the free exercise of individual initiative and protection against abuse, neglect, and exploitation.

<sup>&</sup>lt;sup>1</sup> Adapted from Administration on Aging, <a href="http://www.aoa.gov/AoARoot/About/Organization/index.aspx">http://www.aoa.gov/AoARoot/About/Organization/index.aspx</a>, August 18, 2009.

#### **Title II: Administration on Aging**

Title II established the Administration on Aging (AoA) within the Department of Health and Human Services. Included among AoA's duties and functions are to serve as an effective and visible advocate for older individuals; collect and disseminate information related to problems of the aged and aging; administer grants; conduct evaluation of programs; provide technical assistance and consultation to states; and stimulate more effective use of existing resources. This title outlines responsibility for elder abuse prevention and services and calls for the development of the Office of the Long-Term Care Ombudsman Program, support for the Aging and Disability Resource Centers (ADRC), and development and implementation of evidence based programs.

#### Title III: Grants for States and Community Programs on Aging

Title III lays out the responsibilities and requirements for State Units on Aging (SUA) and Area Agencies on Aging. It is through the programs and structures established by this title that most of the money is authorized and most of the legislative detail is found.

#### Part A – General Provisions

For a state to participate under Title III, the governor must designate a state agency as the sole agency (State Unit on Aging) to put forth a plan for developing and implementing a statewide aging program. This multi-year plan represents a contract between the state and the federal government for carrying out the programs authorized under the OAA. Like its counterpart at the federal level, the state agency is responsible for serving as an effective and visible advocate for the elderly.

This part directs State Units on Aging (SUA) and Area Agencies on Aging (AAA) to establish comprehensive and coordinated systems to serve older individuals. Also, this part details the formula by which AoA funds are allotted to states. For the most part this formula is based on the number of people aged 60+ in each state and under this provision, preference must be given to providing services to individuals with the greatest economic and social need.

#### Part B – Supportive Services and Senior Centers

This part (Title III B) funds supportive services and senior centers. Supportive services funded under this title are health (including mental health), transportation, information and assistance, housing, long-term care, legal assistance, employment, and crime prevention.

Home and Community Based Services (HCBS), a comprehensive case managed system of care, offers an array of services designed to provide an alternative to nursing home care. Many of these services are funded through Title III B. These services are provided through contracted agencies and may include adult day care, home health aid, housekeeping, personal care, visiting nurse, transportation, in-home and group respite, and other senior center services.

The Legal Services Program offers advice, counsel and legal intervention to older persons on issues such as public benefits, health care, pensions, financial exploitation, consumer problems, advanced directives, and guardianship. These services are primarily provided by local legal service providers in the community funded by area agencies on aging. Some states also operate statewide legal hotlines.

Title III B funding is also used for the Long Term Care Ombudsman Program, which investigates and resolves complaints concerning the health, safety, welfare and rights of residents of long term care facilities; empowers residents and their families to engage in self-advocacy; educates residents and their families about rights and benefits; provides information and consultation for individuals, and advocates for statewide long term care system reform.

#### Part C – Nutrition Service

This part (Title III C) provides for the establishment and operation of nutrition projects both in a congregate setting and for homebound individuals. All meals must meet the requirements for one-third of the dietary reference intakes. However, the nutrition program is more than a meal. It provides nutrition education, counseling, and screening, and often is the gateway to many other services. The law provides that the programs serve at least one meal per day, which may consists of hot, cold, frozen, dried, canned or supplemental foods, five or more days a week except in a rural area where such frequency is not feasible. Congregate meals are served at nutrition sites, including active adult centers, senior centers, schools, churches, and other community settings.

#### • Part D - Disease Prevention and Health Promotion

Disease prevention covers measures not only to prevent the occurrence of disease, but also to arrest its progress and reduce its consequences once established. Under this part (Title III D), the State Unit on Aging is required to provide disease prevention and health promotion services and information at senior centers, meal sites and other appropriate locations. Priority is given to areas of the State which are medically underserved and in which there are a large number of older individuals who have the greatest economic need for such services. A minimum of 25% of Part D funding must be used for activities related to medication management, screening, and education to prevent incorrect medication and adverse drug reactions.

#### • Part E - National Family Caregiver Support Program

The National Family Caregiver Support Program (NFCSP) established under this part (Title III E) serves as a catalyst for the aging network to construct a coordinated system of supports and services to respond to the needs of family or informal caregivers. The FCSP provides the aging network with a range of high-quality services linked through a system to enable family or informal caregivers easy access to the right service at the appropriate time. The major services provided by the FCSP are information for caregivers about available services, assistance for caregivers in gaining access to these services, individual counseling, support groups, caregiver training, respite care, and supplemental services to complement care provided by caregivers.

#### Title IV – Activities for Health, Independence, and Longevity

Under this title, grants or contracts are awarded to eligible public or private non-profit agencies, organizations, and institutions of higher education. Projects may address education and training, research, demonstration of new approaches, and planning activities that prepare communities for the aging of the population. Grants can also be provided for demonstration projects designed to develop aging in place programs and to improve computer training for older adults, transportation services, and multigenerational and civic engagement activities.

#### <u>Title V – Community Service Senior Opportunities Act</u>

This program is designed to foster and promote useful part-time employment training opportunities in community service activities for unemployed low-income persons who are 55 years old or older and who have poor employment prospects. Unlike the other titles of the Act, Title V, commonly known as Senior Community Service Employment Program (SCSEP), is administered by the U.S. Department of Labor.

#### **Title VI – Grants for Native Americans**

This program serves as the focal point for advocacy on behalf of older individuals who are Indians, Alaskan Natives and Native Hawaiians. Supportive and nutrition services that are comparable to services provided under Title III are provided to entities representing American Indian and Alaska Native Tribal organizations and two organizations serving Native Hawaiians. Services are provided in a manner that preserves and restores their dignity, self-respect, and cultural identities.

#### Title VII - Allotments for Vulnerable Elder Rights Protection Activities

This title was created by Congress in the 1992 Amendments to the OAA to protect and enhance the basic rights and benefits of vulnerable older people. This includes individuals who may need advocacy on their behalf because their physical or mental disabilities, social isolation, limited educational attainment or limited financial resources prevent them from being able to protect or advocate for themselves. Services are designed to prevent and remedy abuse, neglect or exploitation.

Title VII has a dual focus. First, it brings together and strengthens three advocacy programs: Long Term Care Ombudsman Program, Programs for the Prevention of Abuse and Exploitation, and State Legal Assistance Development Programs. Secondly, it calls on states to take a holistic approach to elder rights advocacy. States use both Title III and Title VII funds for the Long Term Care Ombudsman and Prevention of Elder Abuse programs.

#### 1.1.2. ARIZONA'S AGING NETWORK

## 1.1.2.1. THE ADMINISTRATION ON AGING (AOA) <sup>2</sup>

The aging network has a federal and a state component (see Illustration 1). The central aging network organization at the federal level is the U.S. Department of Health and Human Services (HHS), Administration on Aging (AoA). AoA is responsible for advancing the concerns and interests of older people and their caregivers and promotes the development of a comprehensive and coordinated system of home and community-based care. AoA is headed by the Assistant Secretary for Aging, who reports directly to the Secretary of the U.S. Department of Health and Human Services. AoA has nine regional offices; Arizona is in Region IX, with the AoA office located in San Francisco.

**United States Congress** U.S. Department of Health and Human **Services** Administration on Aging (AoA) Region IX Office (San Francisco) **Arizona Department of Economic Security** Governor's **Advisory Council** Division of Aging and Adult Services on Aging Area Agencies on Aging Area Agency Advisory Council Service Providers Counties, cities, towns, non-profit, for profit, and faith-based organizations **CLIENTS** 

Illustration 1: Overview of the Organization of Aging Services in Arizona.

The Older Americans Act provides a framework for a partnership among the different levels of government and the public and private sectors with a common objective:

"Improve the quality of life for all older Americans by helping them to remain independent and productive."

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<sup>&</sup>lt;sup>2</sup> For more information, visit <u>www.aoa.gov</u>.

## 1.1.2.2. STATE UNIT ON AGING<sup>3</sup>

State Units on Aging (SUAs) are agencies of state and territorial governments. They are designated by governors and state legislatures to administer, manage, design and advocate for benefits, programs and services for the elderly and their families. In many states, their work extends to adults with physical disabilities. The term "State Unit on Aging" is a general term: the specific title and organization of the governmental unit will vary from state to state. It may be called a Department, Office, Bureau, Commission, Council or Board for the elderly, seniors, aging, older adults and/or adults with physical disabilities. Regardless of the exact title, these state government agencies all share a common agenda of providing the opportunities and supports for older persons to live independent, meaningful, productive, dignified lives and maintain close family and community ties. There are 56 state and territorial units on aging including the District of Columbia, Puerto Rico, Virgin Islands, Guam, American Samoa, and the Commonwealth of the Northern Mariana Islands.

Since 1965, all State Units on Aging have administered the Older Americans Act (OAA) in their respective states, and today it remains the cornerstone upon which all efforts are based. Through a state network of area agencies on aging and service providers, a range of services is provided to older persons. Empowering older persons and their families to make informed decisions and choices is central to the mission of all SUAs. In every state, there is a comprehensive information, counseling, education and assistance system through which consumers are linked to the resources and services they need to remain independent in their homes and communities. In addition, all SUAs have the mission to assure that individual older persons have their civil rights, autonomy and dignity protected, their claims to entitlements honored, and their contracts and covenants for care and benefits fulfilled. States address that mission through the administration of a number of elder rights programs.

SUAs also have significant policy, planning, and advocacy roles in leveraging federal, state, and local public and private funds to support programs on aging. In addition to the federally funded OAA programs, SUAs can administer state funded home and community based programs for older adults, the Medicaid Home and Community Based Services Waiver programs for the elderly (in 28 states, but not Arizona), and/or programs for younger adults with physical disabilities (in 21 states). The goal of these programs is the development of a comprehensive service system that enables individuals to remain independent in their homes and communities and avoid unnecessary institutionalization. Nationally, about a third of the funding provided by the SUAs for home and community services is derived from the federal OAA with the remainder from state and other federal sources.

Lastly, all SUAs play significant roles in ensuring that all older persons have the opportunity to continue productive lives in their communities through the administration of a variety of programs, such as volunteer and intergenerational, employment and training/workforce development, nutritional, health promotion and disease prevention.

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<sup>&</sup>lt;sup>3</sup> Adapted from: National Association of State Units on Aging, <a href="http://www.nasua.org/about\_nasua/state\_units\_on\_aging.html">http://www.nasua.org/about\_nasua/state\_units\_on\_aging.html</a>, accessed August 17, 2009.

#### Arizona's State Unit on Aging<sup>4</sup>

The Division of Aging and Adult Services (DAAS), within the Arizona Department of Economic Security (DES), is Arizona's designated State Unit on Aging. The Federal Older Americans Act provides DAAS with its authority. As the State Unit on Aging, DAAS is responsible for the following:

- Support and enhance the ability of at-risk, disabled, and older adults to meet their needs to the maximum of their ability, choice, and benefit.
- Preserve the rights of individuals and their independence, self-sufficiency, safety, honor, and dignity.
- Assure equal access to quality services, benefits, and supports for individuals.
- Promote opportunities for employment, life-long learning, and civic engagement.
- Assure that opportunities, programs, and services, are designed and developed to meet the needs
  of older Arizonans and prevent premature institutionalization.
- Develop and administer the State Plan on Aging, including the planning, policy development, coordination, priority setting, and evaluation of all State activities related to the objectives of the Older Americans Act.
- Designate a public or private nonprofit agency or organization as the Area Agency on Aging.
- In consultation with the Area Agencies on Aging, develop and publish a formula for distribution within the State for funds received through the Older Americans Act.

#### 1.1.2.3. AREA AGENCIES ON AGING

To enhance the provision of services at the local level, each State Unit on Aging (SUA) is charged with the responsibility of dividing the state into distinct planning and service areas (PSAs) and designating an Area Agency on Aging (AAA) for each PSA. The law provides for some exceptions to this requirement, and there are some states and/or territories that are considered single planning and service areas. There are currently 655 AAAs, with eight of those located in Arizona (see Illustration 2).

AAAs can be non-profit organizations or be associated with councils of governments. An AAA is designated by the State Unit on Aging to assess the needs of older persons within their respective PSA and develop and administer an area plan for services to the elderly. Based on this area plan, AAAs receive sub-grants or contracts from the SUA's allotment of the Older Americans Act. The AAAs typically contract with a number of service providers in their areas to deliver the services to the community. Some programs are provided directly by the AAA.

Illustration 2: Arizona Area Agencies on Aging			
Name	Region	Counties Served	
Area Agency on Aging, Region One	I	Maricopa	
Pima Council on Aging (PCOA)	II	Pima	
Northern Arizona Council of Governments (NACOG)	III	Coconino, Yavapai & non-Tribal regions in Apache and Navajo	
Western Arizona Council of Governments (WACOG)	IV	La Paz, Mojave & Yuma	
Pinal-Gila Council for Senior Citizens (PGCSCS)	V	Pinal & Gila	
SouthEastern Arizona Governments Organization (SEAGO)	VI	Cochise, Graham, Greenlee & Santa Cruz	
Navajo Area Agency on Aging	VII	Residents of the Navajo Nation	
Inter-Tribal Council of Arizona (ITCA)	VIII	Member Tribes of the ITCA	

<sup>&</sup>lt;sup>4</sup> Adapted from DES website, Division of Aging and Adult Services, https://www.azdes.gov/common.aspx?menu=36&menuc=28&ID=8188, 7/10/09.

#### 1.1.2.4. VALUES AND GOALS

Arizona's aging network facilitates individual choice and access to services, allowing individuals to remain at home and maintain as much of their independence as possible by relying on family, friends, and service providers for the tasks they are unable to do for themselves. Research demonstrates that HCBS is generally a cost-effective choice that meets the needs of individuals requiring assistance with mobility or self care. Thus, the Arizona Department of Economic Security - Division of Aging and Adult Services (DES-DAAS), as well as the Arizona Health Care Cost Containment System (AHCCCS)/Arizona Long-Term Care System (ALTCS), and the Arizona Department of Economic Security - Division of Developmental Disabilities (DES-DDD) all offer options to age in place, while providing services that promote independence and dignity for individuals.

Area Agencies on Aging coordinate and offer services that help older adults remain in their home — when it is their preference to do so. The availability of home and community-based services makes independent living, even in remote areas, possible. The AHCCCS/ALTCS program has long been recognized as a national Medicaid LTC model for its significant cost-effectiveness due primarily to the state's unusually strong reliance on community-based placements and support services in lieu of institutional care for older adults and persons with physical or developmental disabilities. Nearly 70 percent of individuals in the ALTCS Elderly and Physically Disabled (EPD) program in contract year 2008 received home and community-based services.<sup>5</sup>

The goals and strategies expressed in the Arizona State Plan on Aging reflect the focus on assisting individuals, their families, and their caregivers remain self-sufficient and access services that support their preferences and needs. The mission, vision and guiding principles of DES reflect this reliance on HCBS and the value placed on avoiding unnecessary placement of individuals in care facilities.

#### **DES Mission:**

The Arizona Department of Economic Security promotes the safety, well-being, and self sufficiency of children, adults, and families.

#### **DES Goals**

- Strengthen Individuals and Families
- Increase Self-Sufficiency
- Develop the Capacity of Communities

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<sup>&</sup>lt;sup>5</sup> Arizona Health Care Cost Containment System, "Annual HCBS Report (CY 2008)."

#### **DES Guiding Principles include the following:**

#### Systems of care must:

- be customer-and family-driven
- be effectively integrated
- protect the rights of families and individuals
- allow smooth transitions between programs
- build community capacity to serve families and individuals
- emphasize prevention and early intervention
- respect customers, partners, and fellow employees

#### Services must:

- be evaluated for outcomes
- be coordinated across systems
- be personalized to meet the needs of families and individuals
- be accessible, accountable, and comprehensive
- be culturally and linguistically appropriate and respectful
- be strength-based and delivered in the least intrusive manner

#### State Plan on Aging 2011-13 Goals

- **Goal 1:** Make it easier for older Arizonans to access an integrated array of state and aging services.
- **Goal 2:** Increase awareness and understanding of aging issues and help prepare Arizona for an aging population.
- **Goal 3:** Increase the ability of older adults to remain active, healthy and living independently in their communities.
- **Goal 4:** Increase the safety and well-being of older Arizonans.
- **Goal 5:** Strengthen Arizona's economy by capitalizing on an integrated and well-trained informal, paraprofessional, and professional workforce.
- **Goal 6:** Enhance the state's capacity to develop and maintain the necessary infrastructure to deliver services in a culturally appropriate, timely and cost effective manner.
- Goal 7: Promote quality of care in all aging services.
- Goal 8: Promote effective and responsive management for all aging services.

#### 1.1.2.5. **SUMMARY**

The Aging network includes numerous organizations and volunteers, both at the federal and the state level (see Illustration 3). For case managers it is important to know about the different programs, their purpose, and how they relate to one another. Each Area Agency on Aging has its own network of providers and volunteers and interacts with numerous community groups, such as advocacy organizations and adult centers.

#### **Important Websites:**

- Administration on Aging: <u>www.aoa.gov</u>
- Division of Aging and Adult Services :

http://www.azdes.gov/daas

Arizona State Plan on Aging:

https://www.azdes.gov/CMS400Min/InternetFiles/Reports/pdf/aging\_state\_plan\_2008\_2010.pdf

Illustration 3: The Aging Network in Numbers (2008)			
Federal			Arizona
56 SUAs	State Unit on Aging		Division of Aging and Adult Services
655	Area Agencies on Aging		8
237	Tribal Organizations		2
10,000	Senior Centers		232
29,000	Providers		165
500,000	Volunteers		336

#### 1.1.3. THE CONTINUUM OF LONG-TERM CARE IN ARIZONA

#### 1.1.3.1. **OVERVIEW**

The aging network plays a major role in the provision of long-term care (LTC) in Arizona. In addition, there are a variety of programs housed in different agencies as well as a large number of providers, coalitions, and associations (see Illustration 4). Coordination of services is very important to ensure appropriate levels and continuity of services. Different laws and funding streams pertain to these programs. This means that policies and procedures (for example, for eligibility) differ and require careful navigation. Efforts to improve communication and coordination include the Interagency Council of Long-Term Care (IACLTC) and AZ Links, Arizona's Aging and Disability Resource Center (ADRC). Intake staff and case managers need to be knowledgeable about all these resources (see diagram below) since they may need to refer or work with clients who are receiving services from multiple sources or have been terminated and need to reconnect to the network.



Illustration 4: Long-Term Care in Arizona

#### 1.1.3.2. PROGRAMS AND SERVICES

#### **Arizona Department of Economic Security (DES)**

The Department of Economic Security is one of Arizona's largest agencies. In addition to the Division of Aging and Adult Services, DES offers numerous programs and services for families, children and adults. This includes employment related services, such as, unemployment insurance and the One-Stop Centers that assist individuals with job search and training. Programs for families include adoption and foster care services, the Division of Developmental Disabilities, and Child Protective Services. DES also conducts the eligibility determination for benefits ranging from Medicare to food stamps. Case managers should be familiar with the Department of Economic Security, specifically the Division of Aging and Adult Services and the Division of Developmental Disabilities. All programs are described on the DES website at <a href="http://www.azdes.gov/daas">http://www.azdes.gov/daas</a>.

#### **Division of Aging and Adult Services (DAAS)**

As described earlier, DAAS is Arizona's State Unit on Aging and administers the following Older Americans Act (OAA) programs:

- Non-Medical Home and Community Based Services
- Nutrition Services (Congregate and Home Delivered Meals)
- Disease Prevention and Health Promotion Services
- Family Caregiver Support Program
- Senior Community Service Employment Program (SCSEP)
- Long-Term Care Ombudsman Program
- Legal Services Assistance Program

In addition, DAAS administers the following programs:

- The State Health Insurance Assistance Program (SHIP)/SMP receives its funding through the Centers for Medicare and Medicaid Services. SHIP assists Arizona's Medicare beneficiaries in understanding and accessing the healthcare benefits to which they are entitled through a network of highly trained volunteers at the community level.
  - The program helps consumers understand their options, secures answers about claims and billing issues, works to resolve disputes between health care providers and insurers, and serves as an advocate in appeals of coverage denials by Medicare, Medicaid or private insurers. The SMP Program provides education on the detection of potential health care system fraud and abuse. Information and assistance is provided through a national toll free number, educational events, and face-to-face counseling.
- **Benefits Checkup** (BCU) is a free, confidential, and quick screening tool for those 55 years and older (or anyone with a disability) to assist them in finding federal and state programs that may improve their quality of life. Screening is done online at <a href="https://www.benefitscheckup.org">www.benefitscheckup.org</a>.
- Arizona Refugee Resettlement Program (RRP) Every year, millions of refugees are forced to flee their home countries due to persecution, war, and human rights violations. Often classified unfairly with economic migrants, refugees flee their country not for economic gain but to escape persecution and threats to their lives. Less than one percent of the world's refugees are accepted for resettlement in a third country like the United States. RRP supports and advances successful refugee resettlement through the coordination of public and private resources that best enable refugees to be firmly established on the path to success and well-being.
- Adult Protective Services (APS) is administered directly by DAAS with offices in every county.
   Adult Protective Services accepts and evaluates reports of abuse, neglect, and exploitation of vulnerable and incapacitated adults and offers appropriate services.
- The Homeless Coordination Office plans and coordinates activities and contracts with community-based organizations and local governments to provide services for homeless and near homeless individuals and families throughout the state. A combination of state, federal and donated funds is used to support local efforts to provide services such as emergency shelter, transitional

housing, case management and outreach. The Homeless Coordination Office is authorized through Arizona Revised Statute 41-1954.

- The Domestic Violence Program works with the statewide Arizona Domestic Violence Coalition, service providers and other state agencies to coordinate services to domestic violence victims. Funding is provided to these groups to assist in the delivery of services to victims and their children. Services provided through these organizations include a crisis hotline, emergency and transitional shelters, counseling, case management, and other supportive services including transportation, child care, legal advocacy and referrals to community programs. A number of resources are available 24 hours a day to assist individuals at risk of or experiencing domestic violence.
- Low-Income Home Energy Assistance Program (LIHEAP) Energy assistance programs, coordinated among federal and state governments and utility companies, are available to help low-income households meet their energy needs. Subcontracted community agencies administer the Low-Income Home Energy Assistance Program (LIHEAP) and the Utility Repair, Replacement and Deposit Program (URRD). These programs assist with utility deposits and bill payments, conduct home weatherization, and repair or replace certain appliances.

#### Community Action Programs

The Community Services Network is made up of public and private agencies that work to alleviate poverty and empower low-income families in communities throughout Arizona. Most of the agencies are Community Action Agencies (CAAs) created through the Economic Opportunity Act of 1964. CAAs provide services to more than 150,000 low income people annually, providing linkages to job training opportunities, GED preparation courses, and vocational education programs. CAAs provide a range of services addressing poverty related problems – from income management and credit counseling to entrepreneurial development and small business incubators; from domestic violence crisis assistance to family development programs and parenting classes; and, from food pantries and emergency shelters to low income housing development and community revitalization projects. DAAS contracts directly with ten Community Action Agencies, one migrant organization and the Arizona Community Action Association. Some of these agencies subcontract with other community agencies within their service delivery area.

## Division of Developmental Disabilities (DDD)<sup>6</sup>

The Division of Developmental Disabilities' services and supports help more than 28,000 individuals with developmental disabilities achieve self-sufficiency and independence. The Division likewise offers supports for family members and other caregivers. The Division believes that people can best be supported in integrated community settings, and the majority of the Division's programs and services are tailored to meet individuals' needs in their home and other community settings.

Services are delivered by Division staff primarily through support coordination (case management) and a large network of individual and agency-contracted providers. Individuals with developmental disabilities and their families have the opportunity to "self-direct" their services, including choice of a Support Coordinator (Case Manager) as well as their providers.

Services include early intervention services for infants and toddlers, ages birth to three years, helping these young children grow and develop and providing support to their families. Services for children and young adults may include specific skills training, assistance with transition from school to work, respite (caregiver relief), behavioral health services coordinated with the Department of Health Services, and assistance with personal care. For adults, supports may include job training, structured daytime activities, skills training, in-home assistance with personal care and other in-home supports.

Many individuals the Division serves qualify for the Arizona Long Term Care System (ALTCS) in which the Division is the program contractor for people with developmental disabilities. Individuals receive acute care services through four contracted health plans as well as long-term care services. This provides a unique opportunity to coordinate services across the whole person – looking at maximum outcomes.

<sup>&</sup>lt;sup>6</sup> Adapted from the website of the Division of Developmental Disabilities, <a href="http://www.azdes.gov/ddd">http://www.azdes.gov/ddd</a>, accessed 8-14-09.

## Arizona Health Care Cost Containment System (AHCCCS)<sup>7</sup>

The Arizona Health Care Cost Containment System (written as AHCCCS and pronounced 'access') is Arizona's Medicaid program. AHCCCS oversees contracted health plans in the delivery of health care to individuals and families who qualify for Medicaid and other medical assistance programs. Eligibility for acute health care services under AHCCCS is largely determined on the basis of financial need. AHCCCS also administers the Arizona Long-Term Care System (ALTCS). AHCCCS typically serves over one million residents in Arizona in its acute care program.

## Arizona Long Term Care System (ALTCS)<sup>8</sup>

The Arizona Long Term Care System (ALTCS) program is for individuals who are 65 or older, blind, or disabled and need ongoing services at a nursing facility level of care. However, program participants do not have to reside in a nursing home. Many ALTCS participants live in their own homes or an assisted living facility and receive needed in-home services. This can include personal care, attendant care, and housekeeping services. ALTCS is administered by AHCCCS, and its programs also use financial need as an eligibility criterion. ALTCS typically serves over 45,000 individuals.

Eligibility for ALTCS is determined by income, resources, and medical criteria. Income and resource limits are posted on the AHCCCS website at <a href="www.azahcccs.gov">www.azahcccs.gov</a>, on the page for applicants. There are specific limits on resources, but ALTCS applicants can exclude assets, such as home equity, a car, burial plot, and life insurance, up to a specified value. There is also a provision that allows spouses living in the community to retain income and resources as mandated by the federal spousal impoverishment guidelines. Some individuals who are denied services through ALTCS may be eligible for services through the NMHCBS system.

AHCCCS also offers services for individuals with a developmental disability, requiring the level of care provided in an Intermediate Care Facility for Mental Retardation and Related Conditions (ICF-MR). Those who qualify do not have to reside in an ICF-MR. Most ALTCS-DD members live in their own homes or in other community settings and receive needed services there.

ALTCS contracts with a number of health plans, called program contractors. Each program contractor provides the same quality services, but each may work with different nursing homes, assisted living facilities, specialists, doctors, dentists, hospitals, and providers of in-home services. Many of these agencies also provide services for the Area Agencies on Aging.

Eligible individuals choose a health plan from the list of ALTCS program contractors. Individuals with a developmental disability are enrolled with the Department of Economic Security, Division of Developmental Disabilities. Native Americans who live on the reservation are enrolled with an ALTCS tribal contractor. Other individuals who are age 65 or older, are blind, or have a disability are enrolled with a program contractor based on their county. Each county has one program contractor except Maricopa County. In Maricopa County, the applicant can choose from four available program contractors.<sup>9</sup>

Similar to the case management system in the Non-Medical Home and Community Based System (NMHCBS) system, ALTCS employs a case management approach for its members, emphasizing a person-centered approach and strength-based assessment. The following description is taken from the AHCCCS Medical Policy Manual (AMPM), Chapter 1600:

Case management is the process through which appropriate and cost effective medical, social and behavioral health services are identified, planned, obtained and monitored for individuals

<sup>&</sup>lt;sup>7</sup> Arizona Health Care Cost Containment System, <a href="http://www.azahcccs.gov/">http://www.azahcccs.gov/</a>

<sup>&</sup>lt;sup>8</sup> Arizona Health Care Cost Containment System, <a href="http://www.azahcccs.gov/applicants/application/ALTCS.aspx">http://www.azahcccs.gov/applicants/application/ALTCS.aspx</a>

<sup>&</sup>lt;sup>9</sup> Arizona Health Care Cost Containment System, <a href="http://www.azahcccs.gov/applicants/healthplans/contractors.aspx?ID=ALTCS">http://www.azahcccs.gov/applicants/healthplans/contractors.aspx?ID=ALTCS</a>.

eligible for ALTCS services. Each individual enrolled as an ALTCS member must receive case management services as specified in the chapter and provided by a qualified case manager.

The process involves a review of the ALTCS member's strengths and needs by the member, his/her family or representative and the case manager. The review should result in a mutually agreed upon, appropriate and cost effective service plan that meets the medical, functional, social and behavioral health needs of the member in the most integrated setting. The case manager must foster a person-centered approach and maximize member/family self-determination while promoting the values of dignity, independence, individuality, privacy and choice. Case management begins with a respect for the member's preferences, interests, needs, culture, language and belief system.<sup>10</sup>

#### Arizona Department of Health Services 11

The Arizona Department of Health Services (ADHS) is responsible for a variety of health concerns, some of which interact with the long-term care system. The mission of the Division of Public Health Services within the Arizona Department of Health Services is to protect and improve the public's health through prevention and control of disease and disability.

The Division of Licensing Services licenses and monitors health and child care facilities and providers throughout Arizona. Licensing inspections, on-site surveys, and complaint investigations are conducted to promote quality care and safety and ensure that performance standards are met for facility operation and maintenance. Skilled nursing facilities and assisted living facilities are licensed and inspected by ADHS.

The Division of Behavioral Health Services administers the publicly funded behavioral health service system to eligible individuals under state programs and federal programs, including title XIX and title XXI of the Social Security Act. In 2008, behavioral health programs served nearly 150,000 individuals with funding in excess of one billion dollars. Delivery of services is managed through contracts with four Regional Behavioral Health Authorities (RBHAs) and five Tribal Regional Health Authorities (TRBHAs) and tribal contractors. 12

#### **Programs for Native Americans**

Arizona is home to over 250,000 Native Americans. Tribal nations and communities offer programs and services for older adults and individuals with disabilities and work with Arizona State agencies such as the Division of Aging and Adult Services, the Division of Behavioral Health Services, and Arizona Long-Term Care Services.

#### Navajo Nation Area Agency on Aging<sup>13</sup>

The mission of the Navajo Area Agency on Aging (NAAA) is to ensure that elders living on the Navajo Nation receive all available benefits and services to which they are entitled, and that these services are provided in a manner which preserves their dignity, self-respect and cultural identity. Services include elder care, home care, and a senior citizen center. The Navajo Nation Council on Aging (NNCOA) assists in carrying out the Navajo Area Agency on Aging (NAAA) mission to develop and coordinate community-based services for all Navajo elders in the Navajo Nation planning and service area. The NNCOA is comprised of 10 Navajo elderly persons selected from local senior councils.

<sup>&</sup>lt;sup>10</sup> Arizona Health Care Cost containment System, AHCCCS Medical Policy Manual, p. 1610-1, http://www.azahcccs.gov/shared/Downloads/MedicalPolicyManual/Chap1600.pdf

<sup>&</sup>lt;sup>11</sup> Arizona Department of Health Services, <u>www.azdhs.gov</u>

<sup>&</sup>lt;sup>12</sup> Arizona Department of Health Services, "Behavioral Health at a Glance," <a href="http://www.azdhs.gov/bhs/DBHSATAGLANCE.ppt#257.7">http://www.azdhs.gov/bhs/DBHSATAGLANCE.ppt#257.7</a>, Division of Behavioral Health Services

<sup>&</sup>lt;sup>13</sup> Adapted from Navajo Area Agency on Aging, http://www.naaa.navajo.org/index.html

#### Inter-Tribal Council of Arizona<sup>14</sup>

The Inter-Tribal Council of Arizona was established in 1952 to provide a united voice for tribal governments located in the State of Arizona to address common issues of concerns. In 1975, the council established a private, non-profit corporation, Inter-Tribal Council of Arizona, Inc. (ITCA), under the laws of the State of Arizona to promote Indian self-reliance through public policy development. The purpose of the corporation is to provide the member tribes with the means for action on matters that affect them collectively and individually, to promote tribal sovereignty and to strengthen tribal governments.

ITCA operates more than 20 projects, including the Area Agency on Aging (AAA) Region 8, serving older individuals in tribal communities. As an Area Agency on Aging, the ITCA AAA administers the Older Americans Act (OAA), Title III and VII Programs for seventeen (17) tribal governments in Arizona. ITCA AAA also administers the OAA Title VI Program for four (4) tribes. The ITCA AAA core services include advocacy, nutrition services, supportive services, independence living support services, family caregiver support services, long-term care ombudsman, and program development. The ITCA AAA provides information about Medicare, Medicaid, and other various entitlement programs, and fraud and abuse in the healthcare system through the Public Benefits Outreach Project

#### Indian Health Service<sup>15</sup>

The Phoenix Area Indian Health Service (PAIHS) Office in Phoenix, Arizona, oversees the delivery of health care to approximately 140,000 Native American users in the tri-state area of Arizona, Nevada and Utah. Services include primary care, specialty services, dental services; behavioral health; public health nursing; health education, and environmental health services. The services are provided through nine service units located throughout the tri-state area. The Phoenix Area works closely with the forty tribes within the tri-state area in providing health care services.

The Native American Community Health Center, Inc. (dba NATIVE HEALTH)<sup>16</sup> was started in 1978 as a small community nursing program with initial funding from an Indian Health Service grant. NATIVE HEALTH currently provides a wide range of programs including primary medical, dental, WIC (available at two sites), health promotion and prevention, wellness programs and behavioral health programs. NATIVE HEALTH provides services to over 12,000 individuals per year.

#### Resource links:

Arizona Department of Health Services - Native American Liaison, <a href="http://www.azdhs.gov/phs/tribal/">http://www.azdhs.gov/phs/tribal/</a> AHCCCS Information on American Indian Health, <a href="http://www.azahcccs.gov/tribal/default.aspx">http://www.azahcccs.gov/tribal/default.aspx</a> Indian Health Service, Phoenix Area,

http://www.ihs.gov/FacilitiesServices/areaOffices/Phoenix/phx\_services.cfm

Intertribal Council of Arizona, <a href="http://www.itcaonline.com/about.html">http://www.itcaonline.com/about.html</a>

Native Health, <a href="http://www.nativehealthphoenix.org/">http://www.nativehealthphoenix.org/</a>

Navajo Area Agency on Aging, http://www.naaa.navajo.org/index.html

<sup>&</sup>lt;sup>14</sup> Adapted from Intertribal Council of Arizona, <a href="http://www.itcaonline.com/about.html">http://www.itcaonline.com/about.html</a>.

<sup>&</sup>lt;sup>15</sup> US Department of Health and Human Services, Indian Health Services, <a href="http://www.ihs.gov/FacilitiesServices/areaOffices/Phoenix/">http://www.ihs.gov/FacilitiesServices/areaOffices/Phoenix/</a>.

<sup>&</sup>lt;sup>16</sup> Native Health, http://www.nativehealthphoenix.org/about-us.html.

#### 1.1.3.3. COORDINATION OF SERVICES

#### The Interagency Council of Long-Term Care

The purpose of the Interagency Council of Long-Term Care (IACLTC) is to "help the State achieve a coordinated long-term care services delivery system." It does so by recommending methods to develop and implement a coordinated long-term care services delivery system and defining the State's long-term care obligations. The Directors or their designees from the following state agencies comprise the mandated state agency representation on the Council: Department of Health Services, Department of Economic Security, Arizona Health Care Cost Containment System, Department of Commerce and the Department of Insurance. Also on the Council are the Governor's Advisory Council on Aging and the Governor's Council on Developmental Disabilities. Non-voting members of the Council include two Senators and two members from the House of Representatives. The annual report of the Council is available on the IACLTC home page of the DES website at

https://www.azdes.gov/common.aspx?menu=36&menuc=28&id=8752.

#### AZ Links: Arizona's Aging and Disability Resource Center (ADRC)

AZ Links is Arizona's Aging and Disability Resource Center (ADRC). The ADRC is a collaborative effort of the Administration on Aging (AoA) and the Centers for Medicare & Medicaid Services (CMS), designed to streamline access to long-term care. The ADRC initiative is part of a nationwide effort to restructure services and supports for older adults and younger persons with disabilities and it complements other long-term care system change activities designed to enhance access to community living. The goal of the ADRC program is to empower individuals to make informed choices and to streamline access to long-term support. The vision is to have Resource Centers in every community serving as highly visible and trusted places where people can turn for information on the full range of long-term support options.

The ADRC Partners serve as integrated points of entry into the long-term care system, commonly referred to as "one stop shops," and are designed to address many of the frustrations consumers and their families experience when trying to access needed information, services, and supports. Integrated points of entry strive to create community-wide service systems that reduce consumer confusion and build consumer trust and respect by enhancing individual choice and informed decision-making. This strategy can also help to break down barriers to community-based living by giving consumers information about the complete spectrum of long-term care options.

AZ Links (<a href="www.azlinks.gov">www.azlinks.gov</a>) is the website developed in support of the ADRC in Arizona. It contains links to numerous resources on topics from housing to healthcare, employment, and legal resources. The site lists local and national organizations, providers, and support groups. One aspect of the ADRC is options counseling, which provides education and decision aids to individuals, who are evaluating their options for future needs. The online Options Counselor is accessible from the AZ Links website.

Both the AZ Links and Options Counselor websites can be good tools for case managers in researching resources. Clients and their families should also be told about these websites. Key partners in the ADRC in Arizona are DAAS, DDD, ADHS, AHCCCS/ALTCS, AAAs, and other community organizations, such as the centers for independent living (CILs).

<sup>&</sup>lt;sup>17</sup> Interagency Council on Long-Term Care, homepage, <a href="https://www.azdes.gov/common.aspx?menu=36&menuc=28&id=8752">https://www.azdes.gov/common.aspx?menu=36&menuc=28&id=8752</a>

<sup>&</sup>lt;sup>18</sup> Adapted from Aging and Disability Resource Center, "About ADRC," <a href="http://www.adrc-tae.org/tiki-index.php?page=ADRCHomeTest">http://www.adrc-tae.org/tiki-index.php?page=ADRCHomeTest</a>, retrieved 8-19-09.

#### 1.1.3.4. FUNDING OF PROGRAMS

## Aging Services Authorized by the Older Americans Act and Funded via the Administration on Aging:

- Access Services, such as transportation, outreach, information and assistance, and case management
- Disease Prevention and Health Promotion Services
- In-home services, such as, personal care, housekeeping, home health aid, visiting nursing services
- Family Caregiver Support Services
- Legal Services Assistance
- Long-Term Care Ombudsman:
- Multipurpose Senior Centers
- Nutrition Services
- Senior Community Service Employment Program (Note: Authorized by the OAA; funding is allocated through the U.S. Department of Labor)

#### Aging Services Funded by the State of Arizona

The services listed here are funded by the State of Arizona and complement those mentioned above, but also cover those eligible individuals who are 18 years and older. Funds are appropriated by the Arizona State Legislature from the State General Fund. In addition, a portion of the State's Social Services Block Grant (SSBG) funds is used for aging services.

Title XX of the Social Security Act makes block grant funds available to States to help them achieve a wide range of social policy goals. These include "preventing child abuse, increasing the availability of child care, and providing community-based care for the elderly and disabled." <sup>19</sup>

- Adaptive Devices
- Adult Day Care
- Adult Protective Services
- Attendant Care
- Case Management
- Congregate and Home Delivered Meals
- Home Health Aid and Visiting Nurse Services
- Housekeeping Services
- Long-Term Care Ombudsman
- Personal Care Program
- Respite Services

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<sup>&</sup>lt;sup>19</sup> "Social Services Block Grants," The Almanac of Policy Issues, <a href="http://www.policyalmanac.org/social\_welfare/archive/ssbg.shtml">http://www.policyalmanac.org/social\_welfare/archive/ssbg.shtml</a>.

#### Other Programs and Funding Sources

- State Health Insurance Assistance Program (SHIP): SHIP receives its funding through the Centers for Medicare and Medicaid and the Administration on Aging.
- Arizona Long Term Care System (ALTCS): Medicaid is a joint federal-state health care program, primarily for low-income individuals and families. The Centers for Medicare and Medicaid Services (CMS) distribute federal funds to states based on a matching formula. In Arizona, the state pays 33.5% of Medicaid expenditures; the ALTCS program consumes about one quarter of all AHCCCS spending.<sup>20</sup>
- Division of Developmental Disabilities (DDD): DDD operates under several appropriations. In addition to ALTCS funding, there are the 100 percent State funded budget for persons and services that do not qualify for ALTCS, as well as client contributions, third party liability collections, grants and other fund sources. For ALTCS members, DDD receives a fixed amount ("prospective capitation") that is negotiated every year based on actual expenditures in the previous year.
- Behavioral Health (BH): Funding is derived from a variety of sources, including Title XIX (Medicaid) of the Social Security Act, federal block grants, state appropriations and intergovernmental agreements.<sup>22</sup>

<sup>&</sup>lt;sup>20</sup> Kaiser Family Foundation, Arizona Medicaid Spending, <a href="http://www.statehealthfacts.org/profileind.jsp?cat=4&sub=47&rgn=4">http://www.statehealthfacts.org/profileind.jsp?cat=4&sub=47&rgn=4</a>, accessed 8-19-09.

accessed 8-19-09.

21 Division of Developmental Disabilities, Policy and Procedures Manual, Chapter 200, <a href="https://www.azdes.gov/main.aspx?menu=96&id=2844">https://www.azdes.gov/main.aspx?menu=96&id=2844</a>

<sup>&</sup>lt;sup>22</sup> Department of Health Services, "Behavioral Health at a Glance," <a href="http://www.azdhs.gov/bhs/DBHSATAGLANCE.ppt#257,7">http://www.azdhs.gov/bhs/DBHSATAGLANCE.ppt#257,7</a>, Division of Behavioral Health Services.

#### 1.1.4. DAAS POLICIES AND PROCEDURES

There are different levels of regulations and policies, under which the aging network operates. Federal regulations create the framework for aging services, and Arizona has statutes (laws) and administrative rules that apply to service delivery within the state. Building on these federal and state regulations, DAAS has created policies and procedures for its programs and services and the entire non-medical home and community-based service system, including case management. Each Area Agency, in turn, has its own policies and procedures that incorporate relevant DAAS policies and procedures.

#### 1.1.5. REGULATIONS

- At the federal level, the Older Americans Act (OAA) creates the framework for service delivery.
- At the state level, there are two bodies of documents that apply to service delivery:
  - Arizona Revised Statutes authorize the Department of Health Services (Title 36) and the Department of Economic Security (Title 41). Excerpts are labeled with a title and section number, such A.R.S. § 41-1954. (<a href="http://www.azleg.state.az.us/ArizonaRevisedStatutes.asp">http://www.azleg.state.az.us/ArizonaRevisedStatutes.asp</a>)
    - A.R.S. § 41-1951 et seq. is on the Department of Economic Security.
    - A.R.S. § 41-1954 describes powers and duties for DES, including those related to NMHCBS.
    - A.R.S. § 46-182-84 is on powers, duties, and costs related to carrying out the provisions of the Older Americans Act.
    - A.R.S. § 46-191 includes definitions of terms relevant to long-term care, including case management
  - The Arizona Administrative Code is the official compilation of rules that govern state agencies, boards, and commissions. Title 6 refers to the Department of Economic Security; Title 9 is on Health Services, including behavioral health programs and AHCCCS. Entries are labeled with a title and chapter number such as R6-8-101. (http://www.azsos.gov/public\_services/rules.htm.)
    - R6-8-101 et seg. details Grievances and Hearings
    - R6-8-201 et seg. describes Adult Protective Services
- The DAAS Policy and Procedure Manual, section 3100, describes services and administrative service standards for Non-Medical Home and Community Based Services. Operational procedures include guidelines for case management, so that appropriate services are provided according to an assessed need.
- Detailed information about programs and services are disseminated through "Alerts," posted on the DAAS website. Alerts include funding levels, reporting requirements, policies and procedures, and technical assistance. Visit <a href="https://www.azdes.gov/common.aspx?menu=36&menuc=28&ID=8188">https://www.azdes.gov/common.aspx?menu=36&menuc=28&ID=8188</a>.

#### 1.1.6. DAAS POLICY AND PROCEDURES MANUAL

DAAS publishes its Policy and Procedure Manual, outlining services, eligibility, and service delivery, on the DES website at: <a href="https://www.azdes.gov/common.aspx?menu=36&menuc=28&id=8252">https://www.azdes.gov/common.aspx?menu=36&menuc=28&id=8252</a>.

The purpose of the Division of Aging and Adult Services Policy and Procedure Manual is to document the program policies and requirements implemented by the Division of Aging and Adult Services for program contractors. The manual also provides information regarding the administrative standards for Area Agencies on Aging, Area Plans on Aging, and Services and Programs for Arizonans. Policy changes can stem from several sources, including recently promulgated or revised Federal and State regulations, changes in accepted standards of practice, and emerging technology.

The Division of Aging and Adult Services Policy and Procedure Manual consists of four chapters and a glossary. Each chapter contains sections that provide a policy overview, operational principles, and operational procedures. Exhibits, which pertain to a specific policy, are located at the end of the policy chapter.

**Chapter 1000 – Administrative Standards, Reporting, and Functions** 

Chapter 2000 - Area Plan on Aging

**Chapter 3000 – Services and Programs** 

**Chapter 4000 – Senior Community Service Employment Program (SCSEP)** 

Chapter 6000 - Aging and Adult Services Glossary

**DAAS Policy Exhibits (forms, reports)** 

#### 1.1.7. SCOPES OF WORK

Each service administered by DAAS is described in a Scope of Work (SOW), which is part of the contract between DAAS and the Area Agencies.

A Scope of Work includes the following elements:

- Purpose of the service
- Taxonomy definition
- Actual Service description
- Eligibility for service recipients
- Service Requirements
- Professional Standards and Licensing
- Performance Outcomes and Reporting

The "Actual Service Description" provides details about the service as it has been established. The "Service Requirements" include a detailed list of tasks typically associated with a given service. Service provision should not exceed the scope of work, and not all tasks are required for all clients. SOWs are intended to govern the actual delivery of the service but do not necessarily include all regulations that may pertain to the authorization of that particular service, such as the assessment process leading to authorization. Scopes of work are periodically revised; the current scope for Case Management is in the appendix of this handbook.

#### 1.1.8. LINKS TO POLICIES AND PROCEDURES

Arizona Administrative Code (rules): http://www.azsos.gov/public\_services/rules.htm

#### **Arizona Long Term Care System (ALTCS):**

Chapter 1200 of the AHCCCS Medical Policy Manual (AMPM) covers ALTCS; there is also eligibility

manual: http://www.azahcccs.gov/reporting/PoliciesPlans/manuals.aspx

The Arizona Department of Health Services (ADHS) publishes most of its policies and procedures by division.

Division of Licensing Services: <a href="http://www.azdhs.gov/als/index.htm">http://www.azdhs.gov/als/index.htm</a>

Division of Behavioral Health Services: http://www.azdhs.gov/bhs/index.htm

Arizona Revised Statutes (ARS): http://www.azleq.state.az.us/ArizonaRevisedStatutes.asp

#### **Division of Aging and Adult Services (DAAS)**

Policy and Procedure Manual, Alerts, and other Publications:

https://www.azdes.gov/common.aspx?menu=36&menuc=28&id=8252.

#### **Division of Developmental Disabilities (DDD):**

Policies and Procedures

https://www.azdes.gov/main.aspx?menu=96&id=2844

#### 1.2. LEGAL AND ETHICAL ISSUES

Case managers need to be familiar with a number of statutes and policies that pertain directly to NMHCBS. The following is a summary of important laws and rules; links to Arizona statutes and rules are included where appropriate.

#### 1.2.1. CLIENT RIGHTS AND RESPONSIBILITIES

a. Rights specified by the Older Americans Act

The following rights relating to in-home services for frail older adults are listed in Section 314 of the Older Americans Act. http://www.aoa.gov/AoARoot/AoA Programs/OAA/oaa full.asp# Toc153957687

- 1. The right to be fully informed in advance about each in-home service provided by an agency under this title.
- 2. The right to be informed about any change in such service that may affect the well-being of the individual receiving services.
- 3. The right to participate in planning and changing an in-home service provided under this title unless the individual is declared incompetent by a judge.
- 4. The right to voice a grievance about services received or services not provided, without discrimination or reprisal as a result of voicing the grievance.
- 5. The right to confidentiality of records.
- 6. The right to have one's property treated with respect.
- 7. The right to be fully informed (orally and in writing) of one's rights and obligations before receiving in-home services.

(42 U.S.C. 3030c-1)

b. Additional rights supported by the Arizona State Unit on Aging and the Area Agencies on Aging

In addition to the rights listed above, the Arizona State Unit on Aging (DES-DAAS) and the Area Agencies on Aging also support the following rights for their clients. This list is not intended to be all-inclusive, but it does suggest an outline of the basic principles that should be followed when providing services.

- The right to be treated with respect and dignity.
- The right to self-determination, including participation in developing one's own plan of care.
- The right to refuse any or all portions of the care plan.
- The right not to participate in, or to withdraw from, the process at any time.
- The right to be given a fair and comprehensive assessment of their health, functional, psychosocial, cognitive, economic, and environmental status.
- The right to have access to all needed health and social services.

#### Client Responsibilities<sup>23</sup>

Each client who receives services from the Non-Medical Home and Community Services System agrees to meet his/her client responsibilities, which include, but are not limited to the following:

- The responsibility to provide accurate information regarding physical condition and financial situation and to cooperate with the case manager to determine eligibility.
- The responsibility to participate in developing the service plan and consenting to receive the services in the service plan.
- The responsibility to be available and accept services when they are scheduled and if a scheduled service must be canceled, to give at least a 24-hour notice.
- The responsibility to report any changes that might affect the client's status.
- The responsibility to cooperate with the case manager and service providers, to treat them in a respectful manner and provide a safe work environment.
- The responsibility to report any concerns or problems to the case manager and to work with the case manager and/or service providers to resolve problems.
- The responsibility to report any fraud or abuse.

#### 1.2.2. ABUSE<sup>24</sup>

#### Definition

Adult and child abuse refers to any form of maltreatment of a person by a caregiver, service provider, family member, spouse, or friend. Categories of abuse include:

#### a. Abuse

Intentional infliction of physical harm or unreasonable confinement.

#### b. Sexual Abuse or Sexual Assault

Sexual contact with any person incapable of giving consent or through force or coercion, which means by force or threatening.

#### c. Neglect

Failing to provide a person food, water, clothing, medicine, medical services, shelter, cooling, heating or other services necessary to maintain minimum physical or mental health. Shelter refers to housing but also the environment. Leaving a person in unsafe or hazardous environments can be neglect. For children this also applies to parents leaving a child with no one to care for him/her or leaving a child with a caretaker and not returning or making other arrangements for his/her care.

#### d. Financial Exploitation

The improper or unauthorized use of a person's funds, property, or assets. This includes forgery, stealing money or possessions, or tricking a person into signing documents that transfer funds, property, or assets. For children this also includes using a child for material gain, including forcing a child to panhandle, steal or perform other illegal or involuntary activities.

#### e. Emotional Abuse

Psychological abuse such as name-calling, insults, threats, and intimidation.

<sup>&</sup>lt;sup>23</sup> Adapted from a publication of the Pima Health System, Tucson, Arizona.

<sup>&</sup>lt;sup>24</sup> Adapted from *Principles of Caregiving*, Fundamentals, Arizona, 2008.

#### 1. Risk factors for Adult Abuse

- Previous incidents of domestic violence by spouse
- Financial dependency on the adult by the abuser
- Mental illness of abuser
- Adult children living with older parent
- Abuser isolates adult to prevent the abuse from being discovered
- Caregiver stress

#### 2. Signs of Adult Abuse

- Physical: bruises, broken bones, cuts or other untreated injuries in various stages of healing
- Sexual: bruises around breast or genital area; signs of sexually transmitted diseases (STDs)
- Emotional: adult is upset or agitated, withdrawn, non-communicative, or paranoid
- Neglect: dehydration, malnutrition, pressure ulcers, poor personal hygiene, and unsafe or unsanitary living conditions
- Financial: unusual banking activity; missing financial statements or other personal affects such as jewelry; signatures on checks that do not match adult's signature
- Isolation, lack of communication, not allowing client to talk

#### 3. Prevention

- Community awareness
- Public and professional education
- Caregiver support groups
- Stress management training
- Respite care or in-home services

#### 4. Reporting requirements

#### a. Duty to Report

All persons responsible for the care of an incapacitated or vulnerable adult or child have a duty to report suspected abuse and neglect. This is called **mandatory reporting**. Failure to report is a misdemeanor.

#### b. Reporting

Reports must be made immediately (by phone or in person) to Adult Protective Services or Child Protective Services (depending on the person's age) or to the police.

- If the individual is in immediate danger, call 911.
- If the abuse is not life-threatening, report it to a Supervisor who can assist you in making the report to either of the 24-hour a day statewide reporting lines:
  - Adult Protective Services: 1-877-SOS-ADULT (1-877-767-2385)
  - Child Protective Services: 1-888-SOS-CHILD (1-888-767-2445)

#### c. Immunity

All persons reporting are immune from any civil or criminal liability if the report does not involve any malicious misrepresentation, according to the Arizona Statutes (ARS 46-453).<sup>25</sup>

#### d. Other Legal Terms

- Abandonment is when a family or agency leaves an individual without care or support.
- Assault takes place when an individual intentionally attempts or threatens to touch another
  individual in a harmful or offensive manner without the person's consent.
- **Battery** takes place when an individual harmfully or offensively touches another individual without the person's consent.
- **False Imprisonment** takes place when someone intentionally restricts an individual's freedom to leave a space.
- Invasion of Privacy is revealing personal or private information without an individual's consent.
- **Liability** refers to the degree to which a person or his/her employer will be held financially responsible for damages resulting from negligence.
- **Malpractice** is a failure to use reasonable judgment when applying one's professional knowledge.
- **Negligence** is when a personal injury or property damage is caused by an act or failure to act when an individual has a duty to act.

#### 1.2.3. FRAUD

Case managers need to be aware of the possibility of fraud and abuse of the NMHCBS system, and they can also assist clients and their caregivers or family members in the detection of fraud. Fraud can be defined as purposely billing for services not received and/or not provided. The U.S. Department of Health and Human Services has compiled useful tips for detecting and reporting Medicare fraud, at <a href="http://www.medicare.gov/FraudAbuse/Overview.asp">http://www.medicare.gov/FraudAbuse/Overview.asp</a>. Medicare fraud should be reported to the Office of the Inspector General.

Tips for detection or prevention of Medicare fraud include the following. Be suspicious if:

- providers offer free services or offer to find ways for Medicare to pay for products and services;
- anyone offers "free" consultations or claims to represent Medicare;
- anyone asks for health information or a Medicare insurance claim number; or
- items on a bill do not match products or services actually received.

#### 1.2.4. CONFIDENTIALITY AND PRIVACY

#### a. Arizona Revised Statutes

The case manager should respect the privacy of others and hold in confidence all information obtained in the course of case management services. The concept of confidentiality is central to case management, and Arizona Revised Statute 41-1959 covers guidelines on confidential information; permissible disclosure; rules, and violations. The entire statute is posted on the website of the Arizona legislature, Arizona Revised Statutes, Title 41:

http://www.azleg.state.az.us/ArizonaRevisedStatutes.asp.

<sup>&</sup>lt;sup>25</sup> Arizona Revised Statutes, Title 46, <a href="http://www.azleg.state.az.us/ArizonaRevisedStatutes.asp">http://www.azleg.state.az.us/ArizonaRevisedStatutes.asp</a>.

#### Key points for case managers:

- All persons have a right to privacy. This means that information contained in case records and shared by a person is never to be revealed in casual conversation to anyone, and only when necessary under other professional circumstances. Information that is shared must reasonably relate to the purposes of the inquiring agency and must not be used for commercial or political purposes.
- Information to be safeguarded includes all personally identifiable information, such as names and addresses of applicants, recipients and their relatives; information contained in applications and correspondence; reports of medical examination, diagnostic tests and treatments.
- Information may be released under certain circumstances in communication involving the provision
  of services, to make claims on behalf of the client, and to protect against a clear and substantial risk
  if injury to the client.
- Any violation of this section is a class 2 misdemeanor.

#### b. The Health Insurance Portability and Accountability Act (HIPAA)

## What is HIPAA?<sup>26</sup>

HIPAA, the Health Insurance Portability and Accountability Act of 1996, is a federal law that took effect in 2003. Title I of HIPAA regulates the availability and portability of health insurance. Title II deals with fraud and abuse within the healthcare system and creates guidelines for the use of client information. It describes what must be done to maintain client privacy and lists punishments for anyone caught violating consumer privacy. The Office of Civil Rights of the U.S. Department of Health and Human Services is the agency authorized to enforce HIPAA's privacy regulations.

#### What is confidential?

All information about clients is considered private or "confidential", whether written on paper, saved on a computer, or spoken aloud. This includes their name, address, age, Social Security number, and any other personal information. It also includes the reason the individual needs services, the treatments and medications he/she receives, caregiver information, any information about past health conditions, future health plans, and why the consumer is open to services.

Spoken communication runs the gamut from conducting consumer interviews, paging consumers, whispering in corridors, to talking on telephones. Written communication includes the hard copy of the medical record, letters, forms, or any paper exchange of information. Electronic communication includes computerized medical records, electronic billing and e-mail.

#### **Penalties for Violations**

Revealing any of this information to someone who does not "need to know" it is a violation of a consumer's confidentiality. Agencies and their employees can receive civil penalties up to \$25,000 for the violation and criminal penalties up to a \$250,000 fine and/or 10 years in prison for using information for commercial or personal gain or malicious harm.

#### Relevance to Case Managers in the Arizona NMHCBS System

HIPAA applies to health insurance plans, billing services and providers defined as "covered entities" under HIPAA. Case managers need to be aware of the HIPAA policies of their employers and of other service providers. Agencies employing case managers will address HIPAA as needed in their policy documents and new employee orientations.

<sup>&</sup>lt;sup>26</sup> Adapted from the HIPAA training at the Foundation for Senior Living as used in *Principles of Caregiving*, Fundamentals, 2008.

#### **1.2.5. WAIT LIST**

The HCBS program provides non-entitlement services to eligible individuals within the confines of limited funding. The Intake Unit/Area Agency on Aging shall maintain a waiting list for applicants, when intake to the system is on hold. This can occur in the following circumstances:

- when caseload capacity of the case management system or a particular service has been reached, or
- in the case of funding issues.

A waiting list may be imposed for the entire program or for specific services only. When intake for a particular service is restricted, intake for new clients can be processed, and eligible clients are referred to the appropriate case management agency for an in-home assessment. If eligibility is established, the clients can be opened for the unrestricted services and placed on the wait list for the restricted services.

When the system is at capacity and the entire intake process is on hold, an initial telephone screening can be conducted to evaluate the needs of the applicants.

- If the applicant requires only information or referral, the appropriate steps will be taken to complete this service.
- If the applicant appears to be eligible for services from the preliminary information (medical, ADL/IADL and financial) obtained in the telephone screening, the applicant's name will be placed on the waiting list. The applicant must be informed that there are restrictions and that his or her name will be place on a waiting list.
- If the preliminary information indicates that the applicant is in critical need of services, staff will refer the case to the appropriate case management agency for an in-home assessment. If the case manager confirms the high-risk status, the case will be presented to the appropriate individual or committee for consideration of priority services.

Each Area Agency establishes policies and procedures for maintaining a waiting list, reviewing critical need applicants, and follow-up. Waiting lists should be retained for a period of two years.

#### 1.2.6. SERVICE DENIAL OR TERMINATION

The DAAS Policy and Procedures Manual, section 3123.9 addresses service denial; section 3127.3 covers termination of services (<a href="https://www.azdes.gov/common.aspx?menu=36&menuc=28&id=8252">https://www.azdes.gov/common.aspx?menu=36&menuc=28&id=8252</a>). It is critical that written notification of terminations and/or service denial and the reasons for such action are provided to the individual. Services may be terminated for some of the following reasons:

- voluntarily by the individual;
- the individual no longer requires the services;
- the individual refused the services;
- the individual dies:
- the individual moves out of the planning and service area or the state;
- the individual is accepted by the Arizona Long Term Care System;
- the individual is admitted to a hospital or institution for an indefinite stay; or
- the individual becomes a resident of a long-term care facility.

Termination of services within the service plan or case closures must be forwarded by the case management provider to provider agencies and the Area Agency on Aging within seven business days after the individual's case is closed.

Voluntary service termination may occur when the individual and the case management provider agree that the service needs of the individual have been met. Services may also be terminated if the individual has not cooperated with the delivery of service. Documentation in the case file must support the voluntary termination or lack of cooperation.

#### 1.2.7. GRIEVANCE PROCEDURE

Clients and applicants for services have the right to file a grievance over service delivery or denial or termination of services. Providers of programs and services also have the right to file a grievance if a program is terminated or denied funding. Each Area Agency must have a procedure in place to address such grievances. Arizona Administrative Code Title 6, Chapter 8 (R6-8-101 et seq.) outlines requirements and procedures.

#### **Key points for case managers:**

- Each area agency must have a written complaint resolution procedure, which must be given to clients.
- The procedure must allow for an informal meeting to discuss the complaint. If there is no resolution, the client may appeal.
- The area agency must make a decision about the complaint within 30 days. If the client is
  dissatisfied with the decision, she or he must file a request for a hearing with the DAAS within
  15 days of receiving the decision.
- The decision shall be sent to all parties within 60 days of the request for a hearing.
- Any hearings shall be conducted in an orderly and dignified manner. All hearings shall be open
  to the public, but the hearing officer conducting a hearing may close the hearing to other than
  parties to the extent necessary to protect the interests and rights of the parties.
- A hearing decision shall be rendered exclusively on the evidence and testimony produced at the hearing, appropriate state and federal law, and Department rules governing the issue in dispute.
- All decisions in favor of the appellant apply retroactively to the date of the action being appealed
  or to the date, the hearing officer specifically finds appropriate.

#### 1.2.8. COST SHARING AND VOLUNTARY CONTRIBUTIONS

There are two ways for clients to help defray the costs for services provided under the Older American Act (OAA). Section 315 of the OAA<sup>27</sup> describes the guidelines for any cost sharing and /or voluntary contributions. **Cost sharing** is a payment by the service recipient of a portion of the cost of services. States may impose cost sharing with a sliding fee scale based solely on individual income and the cost of delivering services. Cost sharing cannot be required for the following services:

- Information and assistance, outreach, benefits counseling, or case management services.
- Ombudsman, elder abuse prevention, legal assistance, or other consumer protection services.
- Congregate and home delivered meals.

Cost sharing is also prohibited for any services delivered through tribal organizations and for service recipients who are low-income older individuals with income at or below the federal poverty line. Refer to DAAS Policy and Procedures regarding cost sharing arrangements in Arizona.

**Voluntary contributions** by service recipients, their caregivers or representatives are allowed for all services for which funds are received under this OAA. This includes the services for which cost sharing is prohibited. Area Agencies on Aging may ask for such voluntary contributions but the method of solicitation must be non-coercive. Such contributions shall be encouraged for individuals with a self-declared income at or above 185 percent of the poverty line. The level of contribution must be based on the actual cost of services. Asking for voluntary contributions is a responsibility of the case manager, and Area Agencies and providers of case management will offer training for the case managers on appropriate procedures.

<sup>&</sup>lt;sup>27</sup> Older Americans Act of 2006, <a href="http://www.aoa.gov/AoARoot/AoA\_Programs/OAA/oaa\_full.asp">http://www.aoa.gov/AoARoot/AoA\_Programs/OAA/oaa\_full.asp</a>.

## 2. PART TWO: THE CASE MANAGEMENT PROCESS

## 2.1. INTRODUCTION TO CASE MANAGEMENT

Case management is a coordinated process of obtaining essential resources on behalf of clients in collaboration with both formal and informal sources. Principal components are assessment of needs and strengths, followed by planning, implementing, and monitoring resources to provide appropriate and continuous services for individuals. Case management is characterized by advocacy, communication, and resource management. It promotes quality and cost-effective interventions and outcomes. Case management has enjoyed popularity and success in many areas of health and social services settings, particularly in medical and non-medical long-term care populations.

## 2.1.1. EVOLUTION OF CASE MANAGEMENT IN THE UNITED STATES AND ARIZONA

- 1830s: Interdenominational ministers joined together for mutual aid and consultation in helping the poor. Charity organizations and societies formed. Settlement House Movement begins.
- Late 1950s & early 1960s: Client-level coordination or case management resulted from community action programs.
- 1970s: Case management for specific populations, including the frail elderly, spurred the development of case management programs, as we know them today. Health Care Financing Administration (HCFA) funded community-based long-term care demonstrations.
- 1972: Case management first incorporated in federal legislation (Allied Services Act).
- 1973: The Tucson Council on Aging became the Pima Council on Aging and was designated the Area Agency on Aging by the Pima Association of Governments. This was one of five "care coordination" pilot projects funded across the country, which then became a model for other area agencies on aging.
- 1975: Community Mental Health Centers legislation was designed to develop a community support program to coordinate benefits and maximize access to clients.
- 1981: Waxman-Pepper waivers in the Omnibus Budget Reconciliation Act of 1981 gave the Department of Health and Human Services the authority to grant waivers to states with respect to Medicaid plans and to implement case management systems.
- 1984: National Association of Area Agencies on Aging called for area agencies to be mandated through Title III of the Older Americans Act to ensure that case management be the primary component of community-based long-term care systems.
- 1985: Consolidated Omnibus Budget Reconciliation ACT (COBRA) deemed case management so successful that states could elect to provide case management as an optional service in the Medicaid program without seeking federal waivers.

## 2.1.2. TYPES OF CASE MANAGEMENT

Case management activities range from simple referrals or counseling to a highly complex process including advocacy and management of multiple services. Two types of case management practices are most common when working with older adults:

- 1. **Medical case management** is typically provided by a nurse for individuals with extensive health care requirements. This can include multiple tests, treatments, medications, and procedures that need to be coordinated. Services may be provided by:
  - Managed Care Organizations
  - Insurance Companies
  - Hospitals
- 2. Non-medical case management encompasses a broad array of services, ranging from personal care to home-delivered meals and respite for the caregiver. The case manager typically conducts a home visit to include the client and family members in the process of determining what services to offer. Examples include:
  - Non-medical home and community based services (NMHCBS) provided through Area Agencies on Aging in collaboration with the Arizona Department of Economic Security.
  - HCBS provided through the Arizona Long Term Care System (ALTCS) for ALTCS eligible individuals.

There is some overlap between these two types of case management. Case managers in the non-medical HCBS system can arrange for home health aide or visiting nurse services, and ALTCS members may be eligible for acute health care or placement in a nursing facility.

## 2.1.3. ARIZONA SERVICE DEFINITION FOR NON-MEDICAL CASE MANAGEMENT

The Arizona Department of Economic Security (DES) uses a list of taxonomy definitions for services. <sup>28</sup> The following definition is also included in the Division of Aging and Adult Services (DAAS) scope of work for case management (see appendix).

 A service or process that establishes a relationship with an individual or family in order to enhance their functioning and/or integration into the community. Appropriate services and/or benefits are identified, planned, obtained, provided, recorded, monitored, modified when necessary and/or terminated. This may include assessment to determine their needs and eligibility when applying for/receiving services, assistance in finding necessary resources in addition to covered services to meet basic needs, assistance in obtaining entitlements, communication and coordination of care as well as follow-up of crisis contacts or missed appointments.

<sup>&</sup>lt;sup>28</sup> Department of Economic Security, Taxonomy Definition. <a href="http://www.mag.maricopa.gov/pdf/cms.resource/HSTC\_2009-06-11\_Arizona-Social-Services-Block-Grant-Plan-2009-201041371.pdf">http://www.mag.maricopa.gov/pdf/cms.resource/HSTC\_2009-06-11\_Arizona-Social-Services-Block-Grant-Plan-2009-201041371.pdf</a>

## 2.1.4. OBJECTIVES OF NON-MEDICAL CASE MANAGEMENT

From intake through closure of a case, the objectives of case management include the following:

- Keep the service recipient in the least restrictive environment possible
- Enhance quality of care by providing continuity of services
- Identify and utilize resources within and outside the agency
- Assess strengths and weaknesses of the individual and the family caregiver(s)
- Maximize the potential of individuals to meet environmental challenges
- Integrate formal systems of care with informal systems
- Maximize the capabilities within the formal system to meet the needs of the individual

The following sections of this handbook describe the case management process and the role of the case manager. Several key concepts are discussed, such as person-centered practice, the strength-based approach to case management, and the importance of fostering client choice and self-determination. All of these concepts and practices are part of the Arizona non-medical home and community based service system, and case managers will apply these approaches in their daily work. Consumer direction is a related concept that is becoming more widespread in selected programs, and case managers will want to keep informed on ways to incorporate consumer direction where applicable.

## 2.1.5. THE CASE MANAGEMENT PROCESS

The case management process comprises the following steps:

#### Assessment

- 1. <u>Intake and Screening:</u> When a potential client, or a representative of the individual, calls, initial screening (typically on the phone) determines if a referral for a home visit is appropriate. Alternatives are explored and information is given regarding relevant and available services and resources. Demographic information may be recorded on an intake form.
- 2. <u>Holistic Assessment:</u> The case manager conducts an in-depth assessment of needs and strengths during a home visit. This includes evaluating the health/functional, medical, emotional/psychological, spiritual/religious, and financial status of the individual and family caregivers.

## **Service Planning**

- Design Plan: The service plan is developed collaboratively by the client with the case manager.
  When appropriate, others may be involved in the development of the service plan. The clients' support system will be utilized as an integral part of the service plan.
- 2. <u>Implement Plan / Authorize Services:</u> The case manager links the person and/or caregiver(s) to services offered by the Area Agency on Aging, the community, and private pay services.

## **On-going Case Management**

- Monitor/Follow-up: The case manager provides ongoing monitoring of the client's and/or caregiver's status to determine the adequacy of services, to identify any changes in the client's or caregiver's condition, and to assist with ongoing needs. The case manager is responsible for proper documentation and also follows-up after referral of the client to other services (e.g., ALTCS).
- 2. <u>Advocate:</u> The case manager advocates on the client's behalf with all involved agencies, organizations, and individuals.
- 3. <u>Reassess:</u> The case manager reassesses the client's and/or caregiver's service needs at least once every 90 days.
- 4. <u>Closure:</u> The case manager determines when termination of services is appropriate and the case should be closed.

## 2.2. THE CASE MANAGER

## 2.2.1. ROLES AND RESPONSIBILITIES

- **Gatekeeper:** Screening potential clients and their caregivers for determination of appropriate services, including applying proper regulations and guidelines related to eligibility, prioritization, and authorization.
- **Coordinator/Broker:** Identifying, planning, authorizing, arranging, negotiating, coordinating, monitoring, and managing costs of the service plan.
- **Service Planner:** Developing, recording, and maintaining a service plan. The service plan is an agreement between the client or a caregiver and the case manager, which identifies the services to be delivered, as well as the frequency, duration, and goals of these services.
- **Facilitator:** Assisting the client and/or a caregiver or personal representative to reduce or eliminate barriers to the service plan. This role includes resolving issues, which impede the client's or caregiver's progress and access to services.
- Advocate: Ensuring that the individual and/or informal support system receives appropriate
  services and that the services received are of high quality. The case manager may need to work
  within the requirements of available funding resources. They should also be knowledgeable about
  and use any alternative funding sources/resources that would help clients and their caregivers
  obtain needed services.

## 2.2.2. VALUES AND ETHICAL BEHAVIOR

Case managers hold a position of trust and responsibility. Clients may be vulnerable due to their personal circumstances, but also because they see the case manager as an individual with certain powers. As the case manager develops a relationship with an individual, the caregiver and/or family, it becomes important to keep this relationship purely professional. The case manager is friendly and supportive, but is not a friend. Under no circumstances should a case manager assume or accept responsibility for custody, dispersal, or disposal of a client's property or assets.

Professional boundaries (see below) help maintain a proper relationship; professional organizations have also developed codes of ethics and guidelines for behavior. Consider consulting these sources and also use your colleagues and supervisor as resources if you have questions or concerns.

#### **Code of Ethics of the National Association of Social Workers**

Members of the National Association of Social Workers subscribe to a code of ethics, posted on the association's website at <a href="https://www.naswdc.org/pubs/code/code.asp">www.naswdc.org/pubs/code/code.asp</a>. It includes key principles such as the goal to help people and address social injustice, to respect the dignity and worth of a person, and to behave in a competent, professional manner. The code also offers guidelines for situations that may include boundary issues, confidentiality, and conflicts of interest. The Arizona chapter of NASW maintains a website at <a href="https://www.naswaz.com">www.naswaz.com</a>.

## 2.2.3. BOUNDARIES<sup>29</sup>

### 2.2.3.1. INTRODUCTION

A boundary can be described as a limit or an edge that defines one person as separate from another; it is where "I end and you begin." One's personal boundaries can be looked at as a personal system of setting limits, based on the ideas, feelings, values, wishes, and perspectives that are unique to an individual. Boundaries are learned from families, culture and through interactions with others.

Professional boundaries help define the relationship between the service provider and the client. Healthy boundaries are important for maintaining a good client relationship; it is difficult to maintain and end high quality working relationships without them.<sup>31</sup> A case manager is both the gatekeeper to services and an advocate for the client. The case manager helps the client access services and information, but it is important to keep in mind that termination of services needs to begin with the first visit to the client. The clearer the boundaries have been kept on the part of the case manager throughout the service period, the easier it will be for the client and for the case manager to terminate services.

Due to the differing geographical areas that case managers work in, it is not uncommon for some workers in rural regions to see clients out in the community. It is important to remember that the case manager's purpose is to serve, not to be a friend or a surrogate niece, daughter, son, etc. and to maintain professional boundaries. It is your responsibility as a case manager, not your client's, to maintain proper boundaries. If there is a complaint, it may be necessary for you to demonstrate that the client was not harmed in any way.<sup>32</sup>

## 2.2.3.2. BOUNDARY VIOLATIONS

Boundary violations occur when someone knowingly or unknowingly crosses the physical, emotional, spiritual, or sexual limits of another. Unhealthy boundaries can be troublesome for those in the social service field and can lead to burnout sooner than later. Some examples of boundary violations include:

- Sharing personal information with the client or giving out your private phone number.
- Addressing others with the assumption of familiarity that is inappropriate for a professional relationship, for example, using terms such as "Dear" or "Sweetheart."
- Not maintaining a client's privacy by opening or reading mail, eavesdropping, or searching a client's belongings without permission.
- Not allowing privacy in bedroom or bath.
- Offering additional services, for example, to run errands on your way home.
- Interrupting or answering for another person.
- Giving unsolicited advice.
- Unsolicited touch, sexual innuendos, or hitting.
- Accepting foods or gifts you do not want or should not accept.
- Becoming emotional and engaging in yelling, name-calling, blaming, or criticizing.

<sup>&</sup>lt;sup>29</sup> Sources for this section include Kelly Wolf / Francis Krebs, "Maintaining Professional Boundaries in Interpersonal Work," August 2008, <a href="www.first5scc.org/pdf/JointTraining/BoundariesTrainingCurriculum.pdf">www.first5scc.org/pdf/JointTraining/BoundariesTrainingCurriculum.pdf</a> and Lise Taylor Barbour, MD, FAST FACT AND CONCEPT #172: Professional-Patient Boundaries in Palliative Care, <a href="http://www.mcw.edu/fastFact/ff">http://www.mcw.edu/fastFact/ff</a> 172.htm

<sup>&</sup>lt;sup>30</sup> The phrase where-I-end-and-you-begin is used widely in the literature on boundaries and is not attributed to any particular source.

<sup>&</sup>lt;sup>32</sup> "Maintaining Appropriate Professional Boundaries," Social Work - Practice Guidelines, New York State Education Department, <a href="http://www.op.nysed.gov/swboundaries.htm">http://www.op.nysed.gov/swboundaries.htm</a>.

## **Guide to Maintaining Professional Boundaries**

- 1. Understand the responsibilities and limits of your role as provider of service or assistance to someone. You should be friendly, but you should not become a friend to the client.
- 2. Be aware that professional and personal needs are met through professional service and interaction with colleagues; in addition, case managers receive compensation, vacation, and health insurance. Clients should not be used to meet personal needs.
- 3. Acknowledge your professional power and authority as a case manager, you are perceived by clients to have a certain amount of power.
- 4. Establish a clear understanding with the client about your role and maintain boundaries. Address any boundary issues quickly with the client.
- 5. Keep an emotional distance it is necessary when attending to the needs of another so that the case manager does not get overwhelmed. A case manager has many clients and needs to be able to disassociate from them. Becoming emotionally involved in individual cases would not allow the case manager to provide quality service and may cause burnout.
- 6. Use self-disclosure to illustrate only when it might help the client. Do not talk about your own problems, and do not vent to clients about your job or colleagues.
- 7. Behave with professional integrity. Case managers are obliged to act in the best interest of a client even though this behavior may not serve the professional's needs or interests. It is a professional and ethical responsibility to protect the well-being of the client.
- 8. Interact positively and effectively with the service team. Don't try to be the hero and avoid the "rescue" role.
- 9. Take care of yourself. Don't take work home with you and avoid burnout.

## 2.2.4. SELF-CARE

## 2.2.4.1. INTRODUCTION

Like many other health and human service providers, case managers need to be aware of the dangers of stress and burnout. Case managers are not effective when they cannot sleep or become sick. Self-care includes making time for your own needs and interests and not bringing the needs and worries of your clients into your own home. Lifestyle choices can influence your ability to help others and deal with the stress of your work. The main goal that case managers should strive for is balance. Self-care begins with looking at four different areas of our lives: physical, cognitive, spiritual, and social/emotional.

- (1) Physical: Sleep, Balanced Diet, Physical Activity.
  - Are you getting ample sleep to function well?
  - Does your diet help you feel good?
  - Are you getting enough exercise?
- (2) Cognitive: Reading and Writing, Personal Planning, Visualization, New Learning
  - Do you have a chance to read or write (for pleasure)?
  - Do you have time to do personal planning?
  - Have you had any opportunities for learning something new in the past month?
- (3) Social and Emotional: Empathy with Others, Shared Vision and Dreams, Support Network, Connection with Others
  - Do you have people in your life that give you personal and/or professional support?
  - Do you feel emotionally connected with the important people in your life?
  - Do you have people with whom you can share your visions and dreams?
- (4) Spiritual: Clear Values, Spiritual Practice, Connection with Nature, Participation with Arts
  - Do you take time to clarify your values or what gives you meaning in life?
  - Do you take time for practicing in spiritual or values-based practices or communities?
  - Do you have adequate time to connect with the natural world or participate in artistic expression or appreciation?

Talk to your supervisor, co-workers, and colleagues in the field and get ideas pertaining to what they do. Get professional help or take time off if needed. Set small, realistic goals for yourself and celebrate the small victories. You are worth it!

## 2.2.4.2. COMPASSION FATIGUE AND BURNOUT

Compassion fatigue or burnout are the result of several things, including vicarious traumatization, poor boundaries, and poor self-care. The following are some warning signs of compassion fatigue:

- Anger
- Blaming
- Chronic lateness
- Depression
- Diminished sense of personal accomplishment
- Exhaustion physical or emotional
- Frequent headaches
- Gastrointestinal complaints
- High self-expectations
- Hopelessness
- Increased irritability
- Decreased ability to feel joy
- Low self-esteem
- Sleep disturbances
- Workaholism

Becoming aware that we suffer from compassion fatigue will help us assist our clients. If we do not take care of ourselves, we are no good to those we serve. You may be able to use your peers or a supervisor as a sounding board; it may also be possible to make adjustments to your work schedule. If you experience physical complaints or feel you cannot handle the situation, you should consult a physician or mental health professional.

## 2.2.4.3. BEWARE OF HELPING TOO MUCH: THE DRAMA TRIANGLE

Sometimes, we may help others too much, trying to make decisions for them. When this happens, we can get into a psychologically hurtful pattern of interaction. The "Drama Triangle," a concept developed by psychologist Steve Karpman, <sup>33</sup> is a scenario that can change a supportive relationship and leave everyone involved unsatisfied. Initially, individuals involved are in one of three roles:

- <u>Victim:</u> Often initially played by the service recipient, the Victim appears to suffer a lot and seemingly cannot" solve his/her problem(s). The person playing Victim gets attention and nurturing by being needy and helpless and by being rescued.
- Rescuer: Often initially played by the helper, the Rescuer tries to save the Victim by solving his/her problem(s). In doing so, the Rescuer seeks to get attention and love.
- <u>Persecutor:</u> The persecutor puts others down and apparently causes others' problems. The personplaying Persecutor often does this to feel better about him/herself.

<sup>&</sup>lt;sup>33</sup> Karpman, Steve. (1968). Fairy tales and script drama analysis. *Transactional Analysis Bulletin*, 7(26), 39-43. http://www.karpmandramatriangle.com/dt\_article\_only.html

A number of negative interactions are possible in the Drama Triangle, especially when there is a switch of roles. If the "rescue" is successful, the Rescuer reinforces the Victim's helplessness, making the Rescuer feel superior. However, if the rescue fails, the Victim can react angrily to the Rescuer's failure and may switch to the role of Persecutor: "You're no help at all; I'm calling your supervisor." This can reinforce the Rescuer's own sense of inadequacy ("I did my best, but it wasn't good enough. I let people down.") On the other hand, the Rescuer may feel that his/her efforts are not effective and may switch to persecuting the Victim: "I give up. You're hopeless." This can reinforce the Victim's sense of being a bad person: "You're right. I'm no good."

Helpers can avoid the Drama Triangle if they follow these guidelines.

- Do not:
  - Do not give information that is not requested.
  - Do not tell the person what he/she should do.
  - Do not take over making decisions for him/her.
- Do:
- Provide, or help find, information the person wants if asked.
- Help the person make decisions for himself or herself.

## 2.2.5. PROFESSIONAL QUALIFICATIONS

The following qualifications are included in the case management scope of work:

## **Education and Experience**

- 1. Case managers shall have a bachelor's degree in social work, sociology, psychology, counseling, nursing, or other closely related fields, or have two years' experience in social or health services.
- 2. The Case Management Supervisor must have at least the equivalent of a master's degree or at least four years' experience in social or health services.

#### **Professional Standards:**

- 1. Case Managers must have a thorough knowledge of the services provided by their respective programs and an understanding of procedures for integrating services.
- 2. Case managers should have the knowledge, skills, and experience necessary to assess the client's strengths and need for services and perform the core functions of case management.
- 3. Case managers should ensure that appropriate assistance is given to each client, family member, caregiver, or client's legal representative, by providing accurate and complete information about available services allowing the individual self-directed care.
- 4. Case managers must display effective communication skills and be able to work as part of a team of service providers on behalf of the client.
- 5. Case managers should assume responsibility for their own professional growth and continuing education to enhance their case management skills, and keep up with the many changes of available resources in the health and social service fields.
- 6. Case managers should not engage in any personal relationships with the client, caregiver, or family members that may lead to any personal or professional gain or impair professional judgment.

## 2.3. KEY CONCEPTS

The Older Americans Act (OAA) lists among its objectives for older Americans "(f)reedom, independence, and the free exercise of individual initiative in planning and managing their own lives, full participation in the planning and operation of community based services and programs provided for their benefit, and protection against abuse, neglect, and exploitation."34 Further, Title III of the OAA lists as the purpose for this title to assist State agencies and area agencies on aging in order to "secure and maintain maximum independence and dignity in a home environment for older individuals capable of self care with appropriate supportive services." Case managers can employ the following approaches in order to maximize self-determination, independence, and dignity.

## 2.3.1. PERSON-CENTERED PRACTICE

Person-centered practice is a philosophical approach to providing services.<sup>35</sup> It is highly individualized and designed to respond to the expressed current and ongoing needs, preferences and desires of the individual. "Person centered care evaluates the quality of care being provided and each person's experience of well being, through the eyes of the person receiving that care."<sup>36</sup> Person-centered care is increasingly viewed as an essential aspect of delivering quality care to long-term care patients and residents, and it is promoted by the Administration on Aging (AoA), the Centers for Medicare and Medicaid Services (CMS), and the National Council on Aging (NCOA). A similar concept in the acute health care area is patient-centered care.

In institutional settings, such as nursing homes, person-centered care tries to break with the oftenregimented schedules and practices that structure meals, activities, and sleep cycles around staff schedules rather than the preferences of the individual. All too often, staff may be evaluated more on timely completion of tasks rather than the ability to help people improve their quality of life.<sup>37</sup> Time is an important factor in the provision of services, and in institutions as well as home care, staff will try to be efficient and organized. However, with extra time and assistance many older adults and people with a disability can do many things for themselves, retain functional ability, and increase their enjoyment of life.

## Principles and values of person-centered care<sup>38</sup>

- Every person has strengths, gifts, and contributions to offer.
- Every person has hopes, dreams and desires.
- Each person is the primary authority of his or her life, along with those who help him or her.
- Every person has the ability to express preferences and to make choices.
- A person's choices and preferences shall always be considered.

<sup>&</sup>lt;sup>34</sup> Older Americans Act, 42 U.S.C. 3001, section 101.

http://www.aoa.gov/aoaroot/aoa\_programs/oaa/oaa\_full.asp#\_Toc153957690.

35 Using a person-centered approach is different from consumer-directed (or self-directed) care. Consumer direction means an approach to providing services that allows the client to be responsible for planning, budgeting, and purchasing services.

<sup>&</sup>lt;sup>36</sup> Person Centered Care Advocate, Home Page, <a href="http://www.personcenteredcareadvocate.org/">http://www.personcenteredcareadvocate.org/</a>.

<sup>&</sup>lt;sup>37</sup> Megan, Hannan, "Person-Centered Care Nurtures Social Spiritual Needs of Elders & Caregivers," Almost Home, http://www.almosthomedoc.org/changing/person\_centered\_essay.cfm.

Adapted from: Ohio Person-Centered Care Coalition, www.centeredcare.org/pages/about centeredcare.asp.

## Tips for person-centered service delivery:

- Assessment should include social histories, including careers, family life, personalities and hobbies.
- Service providers need to spend time listening to the client and caregivers.
- Consistent staff assignments encourage relationships between staff and residents.
- Assistance with personal care should consider personal preferences. Caregivers should ask the person when he or she prefers to take a bath, e.g. morning vs. evening.
- Meals should allow individuals to eat on their own schedule and make their own choices.
- Flexible service schedules allow individuals to go to sleep and wake up when they want to.
- Music, TV programs, and activities should be selected based on what the person likes, not based on staff preference.

#### 2.3.2. STRENGTHS-BASED APPROACH

The strengths-based approach, informed by the strengths perspective of social work, is implemented through mutual participation and decision-making among clients, caregivers, and the case manager. The traditional expert - non-expert relationship is replaced by one of collaboration and mutual responsibility. No matter how physically or mentally impaired the older person is, he or she is capable of some degree of involvement. In most cases, the person can participate far more than expected if given time and patience on the part of the caregiver.

## Positive aspects of strengths-based case management

- It focuses on the needs of the whole person, physical, psychological and emotional.
- It identifies supports that already exist and strengths or assets that the client brings.
- It gives older adults choices and enhances their sense of self-respect and control of their lives, allowing them to solve their own problems, thus decreasing the likelihood of unnecessary dependence and learned helplessness.
- It enables the case manager and the client to collaborate in developing and implementing the service plan and case goals.

The client-case manager relationship is one of the most important tools of the strengths model. Through it, the case manager is able to help the client and caregiver bring about the changes that are needed for him or her to continue living at home or in the community. This relationship is fundamental to nurturing the client's potential for learning and change and identifying personal and environmental resources. The process begins at initial contact by engaging older adults in identifying their strengths and supporting them to direct their service plan and make their own choices.

#### **Key Principles of the Strengths-Based Approach**

The strengths-based approach is based on principles that guide the way in which professionals work with individuals.<sup>39</sup> The strengths-based approach has been applied to numerous settings, including counseling of children and the mental health field. Depending on the application, the key principles of the strengths approach can be phrased differently. The following summary is intended for case managers working primarily with older adults. Case managers can use these principles to reframe their attitudes and reshape their role from expert to collaborator.

<sup>&</sup>lt;sup>39</sup> For more information on the principles, see for example, Weick, A., Rapp, C., Sullivan, W. & Kisthardt, W. (1989). A strengths perspective for social work practice. *Social Work,* 34, 350-354; or D. Saleebey (Ed.) (1992), *The strengths perspective in social work practice*. New York: Longman.

## 1. Discovering and building on strengths rather than problems facilitates hope and self-reliance.

Focusing on older people's strengths, interests, and abilities rather than their disabilities, illnesses, and problems enhances their ability to move from dependence to healthy independence. In the strengths model, problems and needs are not ignored; they are perceived as barriers to what people want. For example, an elderly man may want to continue living in his home but refuses publicly funded services to fix the leak in his roof. A case manager could draw on his family resources and his background as a building contractor to identify free community resources to meet his needs while capitalizing on what he wants for his life.

Theoretical and empirical literatures support the premise that older people will experience a higher quality of life if they perceive that they have choices and control over their lives. Increased choice and control have been associated with increased feelings of independence and self-sufficiency. Dependence, on the other hand, can foster low self-esteem, depression, hopelessness, and feelings of incompetence, which can accelerate the onset of illness. Strengths-based processes help to counter such effects by stressing the capacities that a person retains, e.g., the ability to maintain oneself or one's home. A good question to ask is, "What are the strengths that have helped this person to survive?" This question will elicit what the older person has done, can do, and already is doing to live independently.

## 2. Older people have the power to learn, grow, and change.

Central to this principle is the belief in older people's inherent capacity to fulfill their dreams, aspirations, and goals in life, despite advancing age, recurring illnesses, and disability. A practice that focuses on this principle recognizes older adults' untapped possibilities and their capability to learn, to heal, and to better their lives. As loss of health and functional disabilities become pronounced with age, many older adults accept the stigmatization and limits of what other people believe they should and should not do because of their age. However, placing limits on clients' hope because of their age stifles their motivation to want to learn, grow, and change. Subsequently, strengths are easily overlooked in the process of defining the presenting issues.<sup>41</sup>

Based on the belief that clients want to change, the case manager can help clients to overcome past deficits and direct efforts toward the future, assisting clients with learning about options and developing goals. An older woman, for example, may choose to live in her own home instead of moving to an apartment near the central business district. A case manager could help the client and caregiver identify transportation options to support the client's choices.

#### 3. Building relationships is essential and primary to help clients effectively.

This principle emphasizes the importance of developing and nurturing the client-case manager relationship as a prerequisite to success. By engaging clients in relationships, the case manager coordinates, partners, and develops plans that enhance clients' independence. Together they build on personal strengths and manage around weaknesses. The case manager's role is to provide services for clients and continually ask them if they feel the service plan has a positive impact on their lives.

# 4. Older people can participate in decisions, make choices, and determine the direction of the helping process.

Client choice and self-determination are central to this principle. The assumption is that no matter how impaired an older person is, he or she is capable of some level of involvement and participation in the helping relationship. Strengths-based case managers focus on developing a partnership with clients and encourage shared decision-making.

<sup>&</sup>lt;sup>40</sup> Ory, Marcia G., Abeles, Ronald P., and Lipman, Paula D. (1991) Aging, Health, and Behaviour. Sage.

<sup>&</sup>lt;sup>41</sup> Motenko, A.K. & Greenberg, S. (1995). Reframing dependence in old age: A positive transition for families. *Social Work*, 40(3), 382-390.

In the strengths-based model, through collaborative assessment and planning, the case management professional is viewed as the agent, the adviser, or a consultant. As a result, clients know they are "in this together" with their case manager and assume more ownership of the process.

The goal of this principle is to begin where the client is and move with him or her to his or her highest possible level of participation. The case manager's aim is to expand client confidence in making crucial decisions, such as when to seek care, what options to select, and when to move to higher levels. Older adults with disabling mental and medical conditions could choose not to be the director of the helping process; however, opportunities still should be sought to give them the choice to be involved in this process. The case manager's challenge is to be aware of clients' rights and the real limitations of their physical and mental conditions.

# 5. Resource acquisition includes outreach to all community resources, including informal supports.

The entire community is viewed as a reservoir of potential resources. The strengths perspective challenges the notion that only formal, paid services meet an identified need, or that services exist only for those who can afford them. Resource acquisition taps into the naturally occurring supports that exist in every older person's environment, including neighbors, the apartment manager, and civil organizations. Social supports can include family, neighbors, pets, faith-based organizations, and other social contacts that give meaning to the individual's life, e.g., the hairdresser, coffee shop server, and any other helpers that an individual sees frequently. The primary task of the case manager is to find or strengthen existing resources and expand the integration of formal and informal providers.

The ability and intentions of each family member or friend involved with the client must be independently assessed. There are wide differences in the commitment and capacity of family members and other involved individuals to meet the difficult demands of caring for dependent adults. Case managers should attempt to make every effort to maximize the involvement of family members in the adult's plan of care. However, if they are not willing or able to act, they cannot be considered an available service provider. Families are not legally required to provide financial assistance for care to older or disabled adults.

#### 2.3.3. CONSUMER CHOICE

Service option choices should be determined by consumer preference rather than provider availability. The Older Americans Act (OAA) supports case managers acting as agents for the individuals receiving services and not as promoters of an agency providing such services, which would create a conflict of interest. The OAA Amendments of 2006 reflect a philosophy of consumer choice and self-directed care. Potentially lower costs and better outcomes will result when the client's needs and preferences are appropriately met. The following principles promote consumer choice: 42

- 1. Ensure that services are culture and language-appropriate
- 2. Base the service plans on goals
- 3. Use the term "supportive services" rather than treatment or care.
- 4. Facilitate choice in regard to choice of providers and choice of service mix
- 5. Involve the client and family in directing case management and services
- 6. Offer information and education, including access to AZLinks, the Aging and Disability Resource Center website.
- 7. Consider the individual's preferences and values.
- 8. Restore dignity and feelings of self-worth; promote health and socialization.
- 9. Empower the individual to make informed decisions

<sup>&</sup>lt;sup>42</sup> Developed by the DAAS Case Management Handbook Committee, 2009.

## 2.4. ASSESSMENT

As mentioned earlier, case management can be divided into three phases: assessment, service planning, and ongoing case management. Each of these phases will be discussed in detail in the following chapters.

Assessment can be divided further into 1) intake and screening, and 2) in-depth assessment by a case manager. In many agencies, intake and screening becomes part of the central intake function. Central intake staff is typically the first contact for a caller and makes an initial determination about the disposition of the call, either Information and Referral or referral to case management. If it appears that the call should be referred to case management, a standardized intake form is used to gather more information before making the final determination to schedule a home-visit by a case manager (see Illustration 5). In a small number of cases, it may then be determined that case management is not called for, and clients are routed back to Information and Referral services. In some delivery models, the initial phone call is routed directly to the case management provider, who will perform the intake function but can also provide Information and Referral services.

Phone call Screening: determine disposition of the call Information Intake: initial and Referral assessment. collect basic data Information Referral to Case (including private Management, or pay services), acceptance of case if selected services. CM did the intake referrals In-depth assessment with ASCAP or short form by case manager Service Plan for NMHCBS or other services

Illustration 5: Screening and Disposition of the Call

## 2.4.1. INTAKE AND SCREENING

Intake and screening is the process through which the client or referral source first comes into contact with the agency, information is exchanged, appropriateness for services and/or referrals is determined, and referrals are made. At this time it is determined whether a more in-depth assessment is called for. The screening process serves an important gate keeping function for programs and the individuals seeking services. How the individual experiences this first contact can mean the difference between the individual seeking additional needed assistance, or not. Therefore, the professional participating in this process should always keep in mind the impact they may have on the individual. The intake staff member's attitude can make all the difference: Staff should be friendly and caring, not harried or indifferent.

## 1. Building a relationship with the individual

The first step is engaging the individual and developing rapport through good communication and a friendly manner. That is to say to develop a helpful, trusting relationship of acceptance and understanding with the individual. A good working relationship with the individual will encourage the person to participate in identifying his or her own needs, resources, priorities, and capabilities and will empower the individual.

## 2. Gathering and evaluating information

A standardized intake/screening tool (form) is used to gather information and may include the following information (see Illustration 6):

- a. Background information (i.e. name, age, marital status, etc)
- b. Referral source
- c. Income/resources available to the person
- d. Informal and formal support (family, friends, other agencies, etc.) already involved
- e. Level of functioning, such as IADL's/ADL's
- f. Urgency of need (risk, danger to self or others)
- g. Client's perceived needs and interest in receiving case management or other assistance

## 3. Referrals and advocacy

During the intake and screening process, referrals to other agencies are made if determined to be appropriate and necessary. Sometimes this may be all the assistance the individual may need. Other times, an individual may need advocacy and follow-up in the process of accessing resources or services.

#### 4. In-depth assessment, if appropriate

If it is determined that an in-depth assessment is needed, then arrangements will be made for the case manager to go to the home of the individual.

Clients who get to the in-depth assessment are potentially eligible for client-supported services, such as housekeeping, home-delivered meals or home-health aid. Caregivers can also be clients; some make contact via the Internet to connect to a support group.

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III	<u>ustration 6: AAA C</u>	<u>ASE MANA</u>	<u> AGEMEI</u>	NT REFE	ERRAL/II	NTAKE FOR	<u>M</u>				
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14. ADMIT DATE:	D/C D	ATE:		15. PH	YSICIAN:						
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SSI	RX		FINCE			GROOMING					
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21. SIGNATURE: DATE:											

## 2.4.2. ELIGIBILITY, TARGETING AND PRIORITIZATION

## **2.4.2.1. ELIGIBILITY**

Older Americans Act (OAA) services are generally available to individuals who are age 60 and older and their caregivers. While there are no specific financial eligibility criteria for Older Americans Act services, they are generally targeted for low-income, frail seniors over age 60, and minority elders and seniors living in rural areas. Individuals must be given the opportunity to contribute to the cost of the service; however, no one can be denied service due to inability or unwillingness to contribute.

## **Basic Eligibility Groups**

- 1. Individuals 60 years of age or older
- 2. Individuals 18 years of age and older with physical disabilities
- 3. Caregivers of persons age 60 years or older and grandparents or older relative caregivers (55 and over) of children (under 19 years of age)

Many of the services of the OAA are available to anyone within the groups listed above. Examples of these would be access to related services such as outreach, information and referral, or community education. Certain other services, however, are limited and only available to frail older individuals and their caregivers. In Arizona, these are designated as client-supported services and include services such as personal care, adult day care, or respite care for a caregiver. Client supported means that the authorization of services is tied to an assessment of the client (care recipient).

The key to eligibility to these services lies within the definition of "frail." The Older Americans Act defines frail as follows:

The term "frail" means, with respect to an older individual in a State, that the older individual is determined to be functionally impaired because the individual:

- 1. (i) is unable to perform at least two activities of daily living without substantial human assistance, including verbal reminding, physical cueing, or supervision; or
  - (ii) at the option of the State, is unable to perform at least three such activities without such assistance; or
- 2. due to a cognitive or other mental impairment, requires substantial supervision because the individual behaves in a manner that poses a serious health or safety hazard to the individual or to another individual.

The specific services that are client supported in Arizona are defined in Chapter 3100 of the DAAS Policy and Procedure Manual, along with the guidelines for determining whether an individual is considered frail. The current version of the DAAS Policy and Procedure Manual is available online and should be a primary resource when looking at eligibility issues.

Services available to caregivers and grandparents raising grandchildren have some additional eligibility considerations that are covered specifically in Chapter 3600 of the DAAS Policy and Procedure Manual.

## **2.4.2.2. TARGETING**

The OAA amendments require that outreach efforts be undertaken to identify individuals eligible for assistance and inform them and their caregivers of the availability of assistance. The OAA states these outreach efforts must:

- 1. identify individuals eligible for assistance under this Act, with special emphasis on:
  - a. older individuals residing in rural areas;
  - b. older individuals with greatest economic need (with particular attention to low-income minority individuals and older individuals residing in rural areas);
  - c. older individuals with greatest social need (with particular attention to low-income minority individuals and older individuals residing in rural areas);
  - d. older individuals with severe disabilities;
  - e. older individuals with limited English proficiency;
  - f. older individuals with Alzheimer's disease and related disorders with neurological and organic brain dysfunction (and the caretakers of such individuals); and
  - g. older individuals at risk for institutional placement; and
- 2. inform the older individuals referred to in a-g above, and the caretakers of such individuals, of the availability of such assistance.

#### **Definition of Social Need**

The OAA section 102 (24) defines "greatest social need" as the need caused by non-economic factors, which include—

- a) physical and mental disabilities;
- b) language barriers; and
- c) cultural, social, or geographical isolation, including isolation caused by racial or ethnic status, that—
  - (i) restricts the ability of an individual to perform normal daily tasks; or
  - (ii) threatens the capacity of the individual to live independently.

#### **Definition of Economic Need**

The OAA section 102 (23) defines economic need as the need resulting from an income level at or below the poverty line. The federal poverty guidelines are issued annually in the Federal Register by the Secretary of Health and Human Services. 43 Indicators to consider may include:

- A. Inability to private pay for services or private pay source does not exist
- B. Income or expenses do not allow for implementation of service plan

## Factors to consider in determining social need may include:

- No available or willing support system
- Inability to manage supports
- Unreliable support system
- Isolation due to language, culture, and location (i.e. no volunteers)
- Inability to perform normal daily tasks
- Being homebound, i.e. unable to independently leave home for socialization or to meet needs

<sup>&</sup>lt;sup>43</sup> The poverty guidelines are sometimes loosely referred to as the "federal poverty level" (FPL), but that phrase is ambiguous and should be avoided, especially in situations (e.g., legislative or administrative) where precision is important. For more information, visit <a href="http://aspe.hhs.gov/poverty/08poverty.shtml">http://aspe.hhs.gov/poverty/08poverty.shtml</a>.

## 2.4.2.3. PRIORITIZATION

The Older Americans Act of 1965, as reauthorized in 2006, places great emphasis on giving preference for receipt of service to older persons (60+) with greatest economic or social need - with particular attention to low-income minority individuals. The OAA and resulting regulations further stress preference be given to older individuals who reside in rural areas, persons age 60 or over who are frail, homebound by reason of illness or incapacitating disability, including dementia or other mental disabilities, isolated, and also to persons with limited English speaking ability.<sup>44</sup>

The amendments also require that direct service providers serve older low-income minority individuals in their programs in at least the same proportion (percentage) as elderly low-income minority persons who live in the area served by the provider.

The OAA reauthorization of 2006 also specified new priorities for serving caregivers and grandparents as follows:

#### Section 372

- (b) RULE.—In providing services under this subpart—
- (1) for family caregivers who provide care for individuals with Alzheimer's disease and related disorders with neurological and organic brain dysfunction, the State involved shall give priority to caregivers who provide care for older individuals with such disease or disorder; and
- (2) for grandparents or older individuals who are relative caregivers, the State involved shall give priority to caregivers who provide care for children with severe disabilities.

#### Section 373

(2) PRIORITY.—In providing services under this subpart, the State, in addition to giving the priority described in section 372(b), shall give priority—

- (A) to caregivers who are older individuals with greatest social need, and older individuals with greatest economic need (with particular attention to low-income older individuals); and
- (B) to older individuals providing care to individuals with severe disabilities, including children with severe disabilities.

<sup>&</sup>lt;sup>44</sup> Supplemental Security Income (SSI) is not a priority. See <a href="http://www.ssa.gov/ssi/">http://www.ssa.gov/ssi/</a> for more information on SSI.

#### 2.4.3. IN-DEPTH ASSESSMENT BY THE CASE MANAGER

If the intake process determines that a home visit by a case manager is appropriate, a referral to case management is made. A case manager will be assigned to conduct the home visit, meet the prospective client, and complete the appropriate form to document all relevant information. The assessment interview should address strengths and needs of the client and/or caregiver, utilizing a holistic approach that comprises numerous factors. The following section on documentation provides an overview of the forms used in the Arizona HCBS system, followed by an introduction to holistic assessment.

## 2.4.3.1. DOCUMENTATION

Documentation is key to quality case management. It provides a picture of the client and the situation that requires intervention. The information that is recorded will help other people who have a need to access the records. Therefore, it is important that documentation be legible, accurate, and complete.

The Arizona non-medical home and community based service (NMHCBS) system uses standardized assessment forms to record information and actions taken. All Area Agencies on Aging in Arizona and all provider agencies contracted by them use these forms. DAAS Policy and Procedure Manual, chapter 3000, section 3123, specifies the use of these forms, and instructional manuals are available to guide the process of completing the forms. Copies of the assessment forms and instructions for completing them are available through the Area Agencies on Aging.

- Arizona Standardized Client Assessment Plan (ASCAP). This 14-page form allows case
  managers to record information about the potential client, including demographics, functional
  assessment, medical and nutritional status, and service plan authorizations. A home visit is required
  for all individuals assessed with the ASCAP. The ASCAP Manual explains each item of the form
  and how it is to be completed.
- 2. Short Form Intake Document (SFID). This 5-page form is generally used when services are needed for a period less than 90 days. It can be used only to authorize case management, short-term home-delivered meals, and services under the Family Caregiver Support Program, including respite, adult day care, and supplemental services. If the ASCAP was used to authorize home-and-community-based services, the SFID shall not be used. Instructions for completion of the form are included in the ASCAP Manual.
- 3. **Tribal Intake Document.** This 4-page form can be used by tribal agencies to authorize services. The ASCAP must be used to authorize services not listed on the Tribal Intake Document or to authorize Home Delivered Meals for a period longer than 90 days. Instructions for completion of the form are included with the Tribal Intake Document.
- 4. **Kincare Intake Document (KID).** This 4-page form is used to record information on persons determined eligible to receive Kincare Case Management, Kincare Respite Care, or Kincare Supplemental Services. Instructions for completion of the form are included in the ASCAP Manual.

The ASCAP, the SFID, the Tribal Intake Document and the KID instruments shall be completed in accordance with the ASCAP Manual, including completing all mandatory fields, obtaining all necessary signatures and meeting all time frames. Qualifiers may be used in determining eligibility as outlined in the ASCAP Manual.

Some key factors to keep in mind when documenting:<sup>45</sup>

- All aspects of the case manager's involvement with the client and/or family are to be documented to support the assessment, service plan, outcomes, and closure.
- Documentation should be completed in a timely manner.
- The client's name should appear at the top of each page.
- Documentation should be chronologically organized. In the event of a late entry, add the
  information in the first available line. Enter "Late Entry" to identify the entry as being out of
  sequence and enter the time and date of the entry. In the text of the entry, be sure to record the
  time and date, the entry should have been made and the reason as to why the entry is late.
- Use every line for documentation. Do not enter into case notes until the previous entry is signed and dated. Draw a line through unused lines.
- Correct an error by making a single line through the error. Write "mistaken entry," "mistake in entry" or "void" beside or above the entry. Initial and date the mistake. Under no circumstances are erasures or whiteout to be used. Editing documentation may be considered fraudulent.
- Keep abbreviations to a minimum. Any abbreviations used should be uniform throughout the
  organization. In the event there is no uniform abbreviation list consider working on one for the
  organization procedural manual.
- Document what the client says. When directly quoting the client always use quotation marks.
- Describe only what is seen, heard, felt and smelled. Avoid making judgments or your interpretation of what is seen, such as, "Ms. Client cried because she is depressed." A better way to describe this behavior would be "Ms. Client cried during the interview." When opinions are used, they should be identified as such.
- Avoid phrases that are difficult to interpret, such as "a lot," "a little" or "slightly." Be as specific as possible.
- Remember: If it is not documented, it never happened.

For further instructions on completing the ASCAP, the SFID, the Tribal Intake Document, or the KID, consult the ASCAP Manual and the DAAS Policy and Procedure Manual.

## 2.4.3.2. HOLISTIC ASSESSMENT

Assessment refers to a process occurring between case manager and client in which information is gathered, analyzed, and synthesized to provide a concise picture of the client and his or her needs and strengths. Assessment is a fluid and dynamic process that occurs during the entire course of a given case. An assessment is the basis from which the care plan evolves. The form used during the interview, such as the ASCAP, guides the assessment interview, but case managers need to develop interviewing skills that lead to a well-rounded, informative picture of the individual, including his or her strengths, goals, and needs, and the existing support system.

Holistic assessment looks at the individual as a whole, not only at the identified "problem" area. A full assessment will include issues of concern, difficulties and barriers to meeting objectives or maintaining independence as well as personal resources, sources of support, and strengths. A holistic strengths-focused assessment strives to preserve older people's dignity and self-respect by addressing coping strategies and areas of competence. An effective assessment determines sufficient information to

<sup>&</sup>lt;sup>45</sup> Information on key factors of documentation is taken from <u>Dietary Documentation Pocket Guide.</u> Jointly Sponsored by Consultant Dietitians in Health Care Facilities, American Dietetic Association, and Dietary Managers Association, Pam Brummit, MA, RD, LD Editor/Author, 2002.

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enable effective planning of interventions and support; it will include the person's desires, aspirations, skills and talents. Assessments should be free of preconceived ideas or biases regarding aging, disabilities or culture. Rather, it should be open to full inclusion of a person's abilities and diversity, and its role in the search for sources of strength and support. A holistic assessment covers several factors that affect a person's functioning and need for assistance, including the following seven components:

- 1. Health and medical factors
- 2. Emotional/psychosocial factors
- 3. Mental (cognitive) status
- 4. Functional Status
- 5. Social support
- 6. Environmental/safety factors
- 7. Financial Factors

#### 1. Health and Medical Assessment

Health and medical assessment includes a review of current and past medical conditions, symptoms, medications, vision and hearing capabilities, and ability to communicate. The client's self-perception of his/her health is also determined. It involves the status and resources relevant to physical illness and health promotion, including, for example, diet and exercise.

#### 2. Emotional and Psychosocial Assessment

The emotional and psychosocial component of an assessment examines the client's feelings, social functioning, and behavior. The aging process involves numerous changes; disability often is a result of a traumatic event that results in ongoing changes of functioning. Consequently, changes and losses can cause emotional and psychosocial problems for both elderly and younger disabled clients. It is important not to diagnose, but to document clearly and neutrally in order to promote emotional health and refer to appropriate services.

#### 3. Mental (Cognitive) Status Assessment

Assessment of mental, or cognitive, status is essential to a holistic assessment and to assisting the client in living in the most independent setting possible. Mental status is measured by questioning the client to determine cognitive (thinking) abilities, including ability to reason and to make judgments. Some decline in short term memory is often associated with normal aging, any significant level of impairment is due to disease or some other abnormality and should be examined. Case managers can help by carefully observing and objectively recording all indicators of mental status, as well as all indicators of contributing factors, and if necessary, arrange for a professional assessment through a geriatrician or neurophysiologist.

#### 4. Functional Status Assessment

Functional abilities are measured by determining the client's ability to perform personal care tasks and manage household activities. Assessing ADLs and IADLs is basic to a holistic view of a client. Sometimes, the client is not the best source of information about these activities and it is necessary to check with formal and/or informal caregivers concerning the validity of answers. At times, the case manager's own observation skills will help develop a clear picture of the client's true functional abilities. For example, a client might say that there is no problem with ambulation, but a walker can be seen semi-hidden behind some drapes. A full assessment of functioning will include personal status, and the full range of daily living situation such as home environment, transportation, and access to basic material needs.

#### 5. Social Supports Assessment

The support system is evaluated by learning about the client's helping network of family and friends and what kinds of assistance are provided. When needed, the case manager can corroborate the client's report of this information with other reliable sources available. Informal supports frequently make the difference between a successful care plan and one that is unsuccessful. When assessing social supports it is also important to assess the ability of this support to continue and whether it is a positive experience for the client and caregiver. Caregiving can lead to stress syndrome, which is an exhaustion arising from excessive demands that may be self-imposed by families, jobs, friends, values systems, and society. Such stress, in turn, can lead to burnout and inappropriate care giving behaviors. In planning to meet the client's needs, it is essential to understand the caregiving situation.

## 6. Environmental/ Safety Factors Assessment

The choices a person makes concerning his/her environment and what is acceptable reflect his/her individual values, ethics, and principles compiled from a lifetime of experience and history. Objectively assessing the environment and safety is essential to successfully maintaining clients in a setting of their choice. Environment is evaluated by examining the home and living situation for hazards and suitability to the client's level of mobility. For instance, are stairs impossible for Mrs. Smith to climb with her broken hip? Or is the bathroom unsafe for Mr. Thompson to bathe? Is there any equipment available that would enhance their functioning?

#### 7. Financial Resources Assessment

The last component of a holistic assessment is financial resources. Case managers usually identify any potential services for which financial eligibility must be established and may assist the client with this process if needed. The impact of those financial needs must be considered, and understanding the balancing act required by many to keep bills paid is essential to the holistic viewpoint. Without adequate financial resources, clients are forced into decisions that negatively impact every other area of the assessment. Financial status is evaluated by determining the client's income, assets, and expenses, as well as by reviewing his/her eligibility for any entitlement programs.

## 2.5. SERVICE PLANS

Based on the assessment, a service plan is developed and implemented. Services are authorized as appropriate, and case management continues to provide coordination and oversight.

## 2.5.1. DEVELOPING A SERVICE PLAN

The case manager is responsible for coordinating and writing the service plan. The service plan is defined as the process of developing an agreement between client/consumer and the case manager that addresses the client issues and needs, the outcomes to be achieved and the services to be provided to achieve the goal. 46 A service plan is the documentation that supports the service need(s). The strengths and problems of the consumer/client are identified during the assessment process and from this process. The case manager works with the client and his/her caregivers to develop a service plan, utilizing the key concepts introduced earlier.

#### Parts of a Service Plan

The format of the service plan varies from agency to agency; it may be an agency's standardized form or a written narrative. The following items are common components of a service plan; a sample plan is included in the appendix.

- A comprehensive list of needs.
- A desired outcome for each need being addressed.
- The type(s) of help needed to achieve each desired outcome.
- A list of the services and providers that will supply the help.
- An indication of the amount (units) of each service to be provided.
- A calculation of the costs of providing the listed services for a specific period of time and an indication of the sources of payment.
- An indication of agreement by the client and, as appropriate, the caregiver.

Whatever the format, clear articulation of the service plan will promote continuity and consistency of care of the consumer/client by those involved in working with the plan. Where the case manager does both the assessment and the development of the service plan, the processing of information for the plan begins during the assessment process. It is important that time is spent developing a comprehensive service plan including all the following principles to assure that nothing is left out. 47

The following basic principles of a service plan are discussed below. The service plan:

- 1. is based on a comprehensive, holistic assessment;
- 2. reflects the consumer's/client's values and preferences;
- 3. identifies mutually agreed upon goals;
- 4. describes formal and informal resources;
- 5. defines a timetable for achieving objective/goals:
- 6. clarifies roles and responsibilities of all;
- 7. reflects possible costs and payment sources/participant contributions or cost share;
- 8. includes an indication of agreement (signatures).

 $<sup>^{46}</sup>$  Schneider, B. (1988): "Care Planning: The Core of Case Management." *Generations*. 12, No. 5, 16-18.  $^{47}$  Schneider (1988).

#### 1. The plan is based on a comprehensive, holistic assessment

A comprehensive, holistic assessment looks at the individual as a whole, not only at the identified "problem area." For those individuals entering the non-medical home and community based services (NMHCBS) system, the required assessment instruments must be used, such as the Arizona Standardized Client Assessment Plan (ASCAP) or the Short Form Intake Document (SFID). These documents are standardized; therefore, in order to individualize the assessment it is important and necessary that the case manager use the "comment" sections of the form.

## 2. The plan reflect the consumer's/client's values, preferences, and strengths

Autonomy, the right of self-determination or self-rule, is core to the planning process. Client participation in the development of the service plan is essential to the plan's success. Participation in the development of a plan may also need to include family members, significant others, and others involved in the clients care. This may also be defined as a competent person having the right to live life without interference, as long as he/she is not interfering with the rights of others. The competent person is assumed to be "in charge of his/her own case." The service plan of the competent individual should then be based on the consumer's/client/s self-perceived needs.

Even in cases that do not involve questions of competency or the delicate balancing of rights, there are two basic and important implications of autonomy for service-planning practice:

- The client decides whether to accept or refuse any particular care arrangement.
- The case manager will need to provide the client with sufficient information to make an informed decision.

Clients are people who want to go about their daily lives; they just need some help in order to do that. If a case manager (or other human services staff) takes over and shapes a client's life, the case manager will have, in effect, taken the client's life away. When this happens, the client may refuse help, even though the refusal could potentially result in harm. A good strategy for preventing refusal of the service plan is to tailor it as carefully as possible to the individual, the whole individual, not just the objectively viewed needs.

This approach is characteristic for a strength-based assessment, including a personal (consumer/client) goal plan, offering the client the potential to get what he or she needs and wants in life.<sup>48</sup>

#### 3. The plan identifies mutually agreed upon goals

The overall goal of long-term care has been described as offering the opportunity for adequate solutions to the problems of everyday living. Before a goal can be mutually agreed upon, the case manager must have a clear understanding of what a goal represents. A goal is generally more abstract, broad in scope, may not always be directly measured, and may have a long-term perspective. For more information on standards for successful goals, see Illustration 7.

Problem identification or, more positively stated, the presenting issues are the basis of the service plan and should be clearly and simply stated. Goals are then statements of what is to be achieved. A goal must be clearly written in terms of expected outcomes that can be evaluated. The case manager may want to complete a personal goal plan with the client before developing the service plan. See Illustration 8 for a sample goal plan.

From a goal statement, the case manager may develop objectives. An objective is a statement that identifies what will be done to reach the goal. Objectives are to be measurable and should contain action verbs, i.e. to identify, to state, to provide, to arrange.

<sup>&</sup>lt;sup>48</sup> Fast, B., Chapin, R, *Strengths-Based Care Management for Older Adults*. Health Professions Press Inc., 2000.

#### Illustration 7: Standards for Successful Goals

## 1. Stated in positive terms

Stated in terms of what clients are going to do rather than what they are going to stop doing.

For example: Susan will call her daughter when she is low on groceries.

## 2. High probability of success

Each goal must be realistic and achievable. Artificial ceilings should not be placed on clients to prevent goal failure. Client investment and commitment is critical to goal achievement.

For example: Fran will use her walker when she retrieves her dog from outside.

#### 3. Measurable and observable

Goals should have a visible and explicit outcome. Each goal should reflect only one behavioral step.

For example: Fred will take his medications each night during the evening news.

## 4. Specific, small, time limited

Short-term goals should be time limited – no longer than 3 months – and broken down into small steps. A reasonable time frame increases the probability that goals will be achieved.

For example: Jenny will attend senior aerobics twice a week at the senior center.

#### 5. Understandable and meaningful to the client

Clients' ownership of the personal planning process increases when goals are relevant to their needs and reflect as much as possible their own language.

For example: Rita will call Mrs. Smith each week for a ride to her sewing circle.

Fast, B., Chapin, R, Strengths-Based Care Management for Older Adults. 2000 Health Professions Press Inc.

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Illustration. 8: Personal Goa	al Plan (Sample	e)				
For:	Case M	anager:	Date:			
Planned Frequency of Contac	ot:					
Service Plan Focused On:						
☐ Daily Living ☐ Health ☐ Finances/Ir		<ul><li>☐ Social Supports</li><li>☐ Spirituality/Religion</li><li>☐ Leisure/Recreational Interests</li></ul>				
My Long-Term Goal:						
Short-Term Goal (Tasks)	Who is Responsible	Target Date	Date Accomplished	Comments		
Client's signature	Date	Cas	se Manager's sig	anager's signature		
		Colla	Collateral signature			

Source: Fast and Chapin. (2000) Strengths-Based Care Management for Older Adults. Baltimore: Health Professions Press, Inc., p. 67.

Multiple needs can be combined into one statement or broken up into more than one. Remember when lumping problem statements together the potential is there to not be able to identify desired outcomes.

Long-range goals should be broken into manageable parts, assisting the client in prioritizing the short-term goals to address more immediate needs. For any goal or objective to be successful, someone must be assigned the tasks and a timeframe is to be defined. When this step is left out of the service plan, either the goal is not accomplished or the case manager assumes or is assigned by assumption the responsibility to completing the tasks.

## 4. The plan describes formal and informal resources

The case manager will draw from a broad range of community resources to address the client's need. Often resources are described as formal or informal. Generally, the formal resources are those services that are provided by an agency or organization. Many, if not most, of these formal resources are paid services, and the case manager needs to consider availability of funding when authorizing these services. Informal resources may include family and friends, along with neighbors, faith-based organizations, and other support networks; these are typically unpaid. The case manager will depend upon information provided by the client and other individuals present at the time of the assessment to determine which informal resources are available. Formal resources may be found in human service directories, yellow pages, and other community directories. It is critical to keep the list of formal resources current.

## 5. The plan defines a timetable

Care planning requires a timetable for when tasks will start, be reviewed/evaluated and be reauthorized or terminated. The case management policies outline the timetables for various services authorized under the Older Americans Act. However, when other services are incorporated into the service plan, timetables should also be established to assure the plan is carried out.

## 6. The plan clarifies roles and responsibilities of all

To assure the success of the service plan it is essential that any assigned duties are clearly defined. It is not always necessary for the case manager to do it all.

- a. What role is the client able to fulfill?
- b. Are there family members, friends, and neighbors, community groups that are able and willing to assist the client?
- c. Do the client and involved family members fully understand what the provider agency will be doing?
- d. Is the client aware of his/her rights and responsibilities?

All parties involved with the service plan must accept their individual role and the responsibility for that role.

## 7. The plan reflects possible costs and payment sources/participant contributions or cost share

As the case manager reviews possible options with the client and/or family, the potential costs should be addressed. For this reason, the case manager should have knowledge of community resources and any associated fees.

The case manager may be the first person to address with the client and/or family members the programs and services that are available, under the AAA system. Under the Older Americans Act of 1965, as amended 2006, voluntary contributions are allowed and may be solicited. The case manager should have information and knowledge of the suggested contributions from the various AAA service providers for which he/she may be authorizing services. See part one, section 1.2.8 of this handbook for more information on contributions and cost sharing.

## 8. Include an indication of agreement (signatures)

The process of service planning ends when the above steps have been completed and all parties involved accept the plan. At this point, the case manager requests that the client sign the service plan. The client should receive a copy of the service plan.

## Service Planning Tips

- Families and extended families have an important role in many cultures.
- Clearly identify the client's problem. The problem is not a diagnosis or health condition: it is the effect the condition has on the client.
- Take time to confirm the plan, this will aid in assuring the plan will be carried out.
- A reasonable timetable will increase the chance that a goal will be carried out.
- A well-formed goal belongs to the client and is expressed in the client's language.
- In service planning, it is always preferable to do with the client than to do for.

#### 2.5.2. IMPLEMENTING THE SERVICE PLAN

Once assessment and service plan are complete, services are authorized. The case manager shall coordinate with the provider for delivery of services to the client. Service providers include formal and informal resources. Case managers should also provide information about alternate services such as, AHCCCS or ALTCS. For further information on service authorization, refer to DAAS Policy and Procedure Manual chapter 3100, section 3124.

#### **General Principles**

General principles for arranging services include the following:

- Refer services to formal and informal service providers, accommodating consumer choice
- Develop a cooperative relationship with service providers
- Evaluate the provider's capacity to serve the particular client
- Use formal services to supplement rather than replace informal services
- Completed assessment tools (typically the ASCAP) must be forwarded to the Area Agency on Aging as specified in DAAS Policy section 3125.
- Completed service plans must be forwarded to the service providers as specified in DAAS Policy section 3125.

## **Provider Agencies**

Each Area Agency contracts with provider agencies that can provide the home and community based services, such as personal care, housekeeping, or respite. Service providers are authorized a maximum number of units that can be utilized ("opened") each month. Services authorized cannot exceed the number of units available; refer to part one of this handbook, section 1.2.5, for more information on wait lists.

<sup>&</sup>lt;sup>49</sup> Fast and Chapin, 2000.

#### 2.6. ONGOING CASE MANAGEMENT

After implementing the service plan, the case manager continues to have important responsibilities. On-going case management includes the continuing contacts the case manager has with clients, providers and others. Follow-up activities include monitoring, reassessment, revisions, and termination of services.

## **Selected Characteristics of Effective Follow-Up and Monitoring**

- 1. The follow-up and monitoring process facilitates ongoing contact with clients, caregivers, and providers.
- 2. It is important to maintain a good relationship with the client and caregiver(s), both formal and informal, through frequent communication.
- 3. Case managers need to follow-up on observations, questions, and issues that arise.
- 4. Client's representative(s) and/or service provider(s) may be called on to provide information for monitoring.
- 5. Monitoring should never interfere with the relationships clients have with caregivers, family, friends, and others.

#### 2.6.1. MONITORING OF SERVICE PLANS

Monitoring of service plans is necessary to determine whether services are being provided in accordance with the service plan and meet the client's needs.

Monitoring of the service plan is required to determine:

- that the services authorized meet the client's needs;
- that services are being provided in accordance with the service plan;
- the quality of services being provided;
- the client's progress towards established goals and objectives;
- that issues or problems relative to the service delivery process are identified; and
- that a course of action for identified issues or problems is developed.

The DAAS Policy and Procedure Manual, section 3127, describes specific requirements and procedures for the monitoring of service plans, including the following:

- Monitoring may be accomplished through telephone contacts, home visits, or inter-agency case conferences with the service provider.
- Service plans must be monitored every 90 days.
- Home visits are required every 180 days and when service additions or deletions are made.
- When issues or problems are identified, a corrective course of action is developed.
- All monitoring activity must be documented in the client file.

#### **General Principles of Reassessment:**

There are several principles of good practice related to the task of reassessment. Adherence to these principles ensures that reassessments will be done in a timely manner and in such a way that the client's needs will be met. The principles are as follows:

- The assigned case manager shall monitor each client receiving services on a regular basis to ensure provision of quality.
- Every client should be reassessed according to a schedule or when an "event" (such as death of an informal caregiver) necessitates a total re-evaluation of the client's care plan.
- Reassessment should be done in the client's home or, when necessary, in the client's hospital or nursing home room, rather than in the case manager's/service provider's office or over the phone.
- Reassessment should always confirm that the previously prepared service plan continues to be appropriate to the client. If not, the case manager shall prepare a new service plan to better reflect the client's current situation and needs.

After reassessment, an approximate date should be set for the next reassessment.

## Types of events which can precipitate a reassessment:

- Loss of major caretaker through death or a move
- Death of a client's spouse or a member of the household
- Acute medical crisis
- Major deterioration in physical or mental status
- Institutionalization (hospital, assisted living facility of skilled nursing facility)
- Relocation of a client if it will change the service plan substantially (e.g., if the client moves away from neighbors who provided informal support)
- Previously planned termination of services

## 2.6.2. REVISION OF SERVICE PLANS

Monitoring of service plans may result in revisions to the plan, including service continuation, modification, or termination. Case managers act as advocates for the client and must ensure that needs are identified and access to service is facilitated. However, case managers also serve as agents for the system and shall ensure that services are cost effective and that there is equitable allocation of services to all clients. Reduction or termination of services may become necessary and should be considered in the initial creation of the service plan.

The DAAS Policy and Procedure Manual, section 3127, describes specific requirements and procedures for revision of service plans, including the following:

- Home visits are required for service additions or deletions to the individual's service plan.
- Services authorized through the SFID must be redetermined after 90 days. The case manager shall contact the service recipient at least ten days before the end of the 90-day period.

#### **Reduction of Services**

Reduction is the process of reducing the authorized services and/or reducing the authorized units of service for a particular client.

#### Services may be reduced for some of the following reasons:

- 1. Client's condition has improved.
- 2. Client's established goals have been met.
- 3. Client's needs have changed. Other support has been identified to assist the client.
- 4. Funding/budget restraints.

#### Key steps in the reduction process:

- 1. Discuss the reason for reduction(s) with the client.
- 2. Document the reason in the client's file.
- 3. Follow up with the client to monitor the impact of the modification of services.
- 4. Inform the client in writing about the procedures to appeal the decision.

#### **Termination of Services**

Termination is the process that ends the involvement between the client and the case manager.

## Services may be terminated for some of the following reasons:

- 1. Voluntary service termination. This may occur when the individual and the case manager agree that the service needs of the individual have been met. Documentation in the case file must support the voluntary termination.
- 2. Client's death. The case manager must end date the service authorization(s) with the actual date of death.
- 3. Client moves out of the geographical service area.
- 4. Client is accepted by the Arizona Long Term Care System (ALTCS) or another system of care (e.g. hospice). The assigned case managers should coordinate every attempt for a smooth transition, from one program to another.
- 5. Client is admitted to an institution for an indefinite stay.
- 6. Client non-compliance. Services may be terminated if the client has not cooperated with the delivery of service. The lack of cooperation must be documented with specificity. Documentation in the case file must demonstrate attempts at resolution and subsequent service termination.

#### Key steps in the termination process:

- 1. Notify client in writing of the reason for termination.
- 2. Inform the client in writing about procedures to appeal the decision.
- 3. Assist the client with finding other resources when appropriate.

## 3. PART THREE: SUPPORTING INFORMATION

## 3.1. SERVICE POPULATIONS

## 3.1.1. CARE RECIPIENTS

The primary eligibility group for non-medical home and community-based services (NMHCBS) is older adults. Adults over 18 with a disability can also receive services. Despite these clear criteria, there is much diversity among care recipients, and it is important not to stereotype. Older adults are as diverse as younger people, and people with a chronic illness or a disability are as diverse as everyone else, with different cultural influences, different social and family environments, economic situations, and varying levels of activity.

In assessing needs and strengths, it is important not to make assumptions about the kind of assistance that is needed. "Individuals may be frail or athletic, married and caring for their spouse, or widowed and alone, happy or depressed, rich or destitute. They may be caring for grandchildren, disabled adult children, or suffer a disability themselves."50 Their need for services will vary, from assistance with IADLs to personal care and skilled nursing.

Many care recipients have an informal support system through family and friends; many have one or more informal caregivers. An evaluation of the presence and function of such caregivers needs to be part of the assessment process.

## 3.1.2. CAREGIVERS

## **Definition of a Caregiver**

An informal caregiver is defined as an unpaid family member, friend or neighbor who is the primary source of care for an individual with a chronic illness or disability who is unable to care for him/herself. Grandparents raising their grandchildren are also recognized as a growing population of caregivers in the United States. Informal caregivers provide a critical component in assisting with the long-term care needs of a vulnerable individual. According to the National Family Caregivers Association, more than 50 million people provide care to a loved one in a home setting. <sup>51</sup> Nearly every family in America will eventually become involved in the process of caregiving.

#### Roles of the Caregiver

The roles of a caregiver vary according to the needs of the care recipient. These roles can vary from simple assistance or running errands to complex care with instrumental activities of daily living (IADLs) and activities of daily living (ADLs). Caregivers provide love and support by assisting their loved ones with the ability to live independently in their own home as long as possible.

Arizona Disability and Resource Center Manual, Department of Economic Security, p. 14.
 U.S. Department of Health and Human Services, Informal Caregiving: Compassion in Action. Washington, DC: 1998, and National Family Caregivers Association, Random Sample Survey of Family Caregivers, Summer 2000, Unpublished, http://www.thefamilycaregiver.org/who are family caregivers/care giving statstics.cfm.

## Support of Caregivers

Caregiving is an enormous undertaking. Caregivers often become known as the "Hidden Patient." Caregiver energy is often focused on meeting the needs of a care recipient and not attending to the caregiver's own physical and psychological well-being. Problems facing caregivers include increased health problems, legal quandaries, financial pressures, emotional turmoil (increased risk for depression, stress and frustration), family conflicts, social isolation, unmet needs and a lack of relevant, comprehensive and quality information. Consequences of not being able to cope with caregiving can be as extreme as early death. Support for meeting the many challenges of caregiving include:

- Appropriate caregiver training and education
- In-Home and Adult Day Care Respite services
- Support groups and other forms of counseling and intervention for the family
- Assistive and supportive technology
- Comprehensive resource materials and easy access to information

## **Roles of the Case Manager**

The holistic goal of case management is to identify, assess and assist a care recipient and the caregiver(s) to receive appropriate assistance with their needs (see also part 2 of this handbook). The role of a case manager includes the tasks of assessment, evaluation, understanding, authorizing, tracking and referral. A case manager often becomes the "engine" of a care recipient's team, which includes all informal caregivers.

The key functions of case managers include case identification, assessment, care plan design and implementation, service monitoring, and quality assurance. These functions must be applied to caregivers just as they apply to care recipients; in fact, caregivers can become service recipients.

- 1. Case Identification: It is essential to define carefully both the target population of caregivers and their needs and the corresponding resources and services available in a specific locale to meet those needs.
- 2. Assessment: Case managers must be attentive to the content and process of assessment. Content refers to information collected on the characteristics, preferences, needs, capabilities, and resources of the caregiver and the care recipient. The information gathered serves as the basis for establishing goals, priorities, and measurable outcomes for the individualized service plan. If appropriate, an assessment of the caregiver should be completed.
- 3. Service Plan Design and Implementation: Designing the service plan is a collaborative process between the care recipient, the caregiver, and the case manager. The service planning process begins with goal setting, which includes helping caregivers to gain insight into their needs. The case manager may need to explore strategies for helping caregivers accept services, particularly if the caregiver has not reached the point when he or she is receptive to service.
- 4. Service Monitoring and Quality Assurance: Persons with chronic disabilities and their caregivers have changing needs that often require a variety of services from diverse sources and in different care settings. A key function of the case manager is service monitoring to ensure that needs are identified, the care plan is amended if necessary, and there is continuity in care.

# 3.2. THE AGING PROCESS

# 3.2.1. UNDERSTANDING AGING AS A DEVELOPMENTAL PROCESS

All of us get older; however, aging progresses at different rates in different people and in different ways, due to lifestyle, genetic factors and environmental influences. It is important for case managers to understand the normal aging process. The changes that come with age are not necessarily harmful. Hair turns gray and becomes thinner; skin is less elastic and becomes wrinkled; body functions slow. There are many changes that are normal, and aging should be understood as a normal, developmental process.

The stages of development follow patterns that are based on basic principles typical of all people. 52

- Human development is similar in all people. While every person is unique, development occurs in sequences that are predictable.
- Development progresses as an orderly process with stages (patterns) that can be predicted.
  Knowing the predictable sequences of behavior helps in recognizing typical (normal), delayed or
  accelerated patterns of behavioral change and growth and enables family, caregivers, case
  managers, and other professionals to develop individualized programs.
- Physical development affects control of large and small muscles. For children, it includes acquiring large muscle skills such as sitting, crawling, walking, running, and throwing, and developing small muscle skills such as holding, pinching and flexing fingers and toes. For older adults, it includes loss of muscle tone and decreased flexibility.
- Social development is the process of getting to know and value other people. It involves being able to establish and maintain relationships, develop social skills, and getting along with others.
- Emotional development refers to the feelings people have about themselves, other people in their lives and the environment in which they live.
- Cognitive development is the process of learning to think and to reason.
- Self-help is the development of daily living skills such as toileting, self-feeding, dressing and so forth.
- Speech or language development includes the process of learning to communicate with others through verbal or other communication means.

# 3.2.2. PHYSICAL / BIOLOGICAL CHANGES OF AGING

As an individual ages, so does his/her body. It is normal for changes to occur, but many factors are involved, and the effects of normal aging can vary greatly from one person to the next. It is important to know what is normal for any one individual, so that an observer will notice anything that is unusual, which should be reported to a health care provider, case manager, or family member.

<sup>&</sup>lt;sup>52</sup> Adapted from *Principles of Caregiving*, Developmental Disabilities Module, Arizona Direct Care Curriculum Project, 2008.

# 1. Sensory-perceptual changes

# **Vision**

- Cornea flattens, yellows, and thickens, resulting in blurred vision
- Pupil is often obscured by drooping eyelid: reduces amount of light reaching retina
- Lens loses its ability to change shape and eye becomes unable to focus on near objects
- Changes in color vision: difficulty with blue and green hues
- Sensitivity to glare
- Visual difficulties may produce these behaviors:
  - ➤ Hand/eye coordination difficulties
  - > Tunnel vision
  - > Squinting
  - > Uncontrolled eye movement
  - Poor depth perception may cause spilling of food or drink

### Hearing

- Normal hearing loss associated with aging: difficulty hearing if the person cannot see the speaker or if there is background noise
- Loss of sensitivity at higher frequencies
- Decreased ability to locate source of sound
- Increase in ear wax
- Hearing difficulties may produce these behaviors:
  - > Increased volume of speaking, shouting
  - Asking for things to be repeated; confusing words
  - > Blank looks, disorientation, inappropriate responses
  - > Isolation, withdrawal from social participation
  - ➤ Emotional upset, hyperactivity, frustration, anger. It is a typical and normal reaction not to admit having trouble hearing, but to lash out.

### **Taste and Smell**

- Taste buds decline with age, causing declines in flavor identification
- By age 80, about 40% of people have difficulty identifying common substances by smell
- Incidence of gum disease and poor teeth add to problems
- Decreased ability to smell may pose safety risk in the home, e.g. smoke or gas
- Taste and smell difficulties may produce these behaviors:
  - > Loss of appetite because of inability to taste
  - Increase in food intake to achieve some taste
  - Weight gain/loss
  - > Excessive seasoning; increased use of sugar and salt
  - Lack of fluid intake
  - Not reacting to unpleasant odors
  - Increased body odor, overuse of fragrance

### Touch

- Reduced tactile sensations; touch sensations are not sent to brain
- Reduced ability to respond to extreme temperatures (hot or cold)
- Texture, temperatures and other discriminations are more difficult
- Touch difficulties may produce these behaviors
  - Withdrawal from tactile activities, touching other people or touching unfamiliar objects
  - Inability to recognize pain
  - > Skin damage, e.g. from hot water
  - Decreasing mobility

### In summary, some principles to consider in dealing with sensory loss are:

- Understand that all five senses tend to decline gradually throughout adulthood.
- Recognize that it may be challenging to adapt to a sensory loss. It is more difficult to cope with multiple losses than a single loss.
- Learn to recognize how people consciously and unconsciously develop ways to compensate for sensory losses.
- Avoid being overprotective. An impaired person should do as much as possible for him/herself.
- Communicate directly with a hearing or visually impaired person, not through the person's companion.
- To be more effective in your work, get to know and respond to a person's sensory abilities and limitations.

# 2. Physical Changes

# **Movement Control and Musculoskeletal Changes**

- Loss of muscle and bone density decreases movement and increases falls
- Gradual loss of height and decreased mobility
- Difficulty maintaining balance, especially for those who are physically inactive
- Falls are a major cause of nursing home placement
- Movement control difficulties may produce these behaviors:
  - Poor posture, tilting forward
  - Dizziness
  - > Holding on to immobile objects when walking
  - Fear of falling leads to reduced activity, which can lead to increased risk for falls

### Changes to Cardiovascular System and Lungs

- Heart pumps with less force
- Arteries are narrower and less elastic, decreasing blood flow
- Lungs are less elastic and respiratory muscles weaken
- Changes to heart and lungs may produce these behaviors:
  - Labored breathing
  - Needing to rest more frequently
  - Changes in exercise level

# **Changes to Digestive and Urinary Systems**

- Decreased saliva production and difficulty swallowing
- Difficulty digesting fatty foods
- Loss of teeth
- Decreased digestive activity, constipation
- Changes in urinary frequency and urgency
- Changes in urinary and digestive systems may produce these results:
  - Getting up at night to use the bathroom
  - > Urinary tract infections
  - > Decreased food consumption or avoiding food that is difficult to chew
  - Lack of willingness to participate in activities that do not allow for easy access to bathrooms

### **Changes to Integumentary System (Skin)**

- Skin becomes less elastic and wrinkles
- Fatty tissue is lost; skin sags
- Loss or thinning of hair; increased facial or body hair
- Changes in the skin may produce these results:
  - Skin is easily bruised or injured
  - > Brown spots on hands and wrist
  - > Skin irritation from water and soaps
  - > Increased use of blankets and sweaters; setting thermostat at higher temperature

# 3. Cognitive Changes

- Reflexes are slower
- Older adults may process information more slowly than younger adults
- Older adults may have decreased short-term and working memory capacity
- Though slower, older adults can be just as effective at learning and making decisions, given the use of expertise, strategy learning, and/or extended practice
- Cognitive difficulties may produce these behaviors:
  - > Temporary confusion or disorientation
  - > Anger and frustration with everyday activities
  - Depression
  - Social withdrawal
  - > Sleep patterns change

### 3.2.3. PSYCHO-SOCIAL ASPECTS OF AGING

### Family and Friends

Most older adults have living relatives and friends with whom they remain in contact. Family and friends provide about 80% of the support needed by the elderly.

#### **Roles and Activities**

Roles are functions that people have in relation to others. As the individual ages, his/her roles and activities will change in all areas of life, including family, work, and recreation. These changes are stressful whether they are positive (such as, becoming a grandparent) or negative (for instance, the death of a spouse). However, the vast majority of older adults report that they are able to adjust and compensate with new activities filling their time. Caregivers and providers of services should be careful to use age-appropriate language and behaviors. Older adults may need help with certain aspects of daily life, but at no time should they be treated as if they were "like children."

### **Living Arrangements**

Most older adults live with a spouse, a partner or alone. Only about 5% of the elderly live in institutions. Assistive devices and adaptations to the home can greatly improve the ability of older adults to function independently, for example, by adding grab bars in bathrooms and choosing a home without stairs.

### **Personality and Attitudes**

There are a variety of personality types among older adults just as there are among youths. The only consistent personality change with age is a tendency for some older individuals to become more preoccupied with fulfilling personal needs.

Older persons tend to have different attitudes than younger people, but this appears to be due to the difference between the cultural environments in which the older adult grew up. While older people tend to be more stable in their attitude than younger people are, they can change and adapt.

#### **Motivation and Interests**

The desires for growth and self-expression continue as we age, although there is a greater tendency to be concerned with security and the relief of anxiety. Older and younger adults tend to have similar interests, and involvement in activities, clubs, or civic engagement should be encouraged. Interest in physical activity tends to decline with age, but exercise is beneficial to most people even at an advanced age. A good social support network and regular physical activity may help prevent or delay cognitive decline.

# Sexuality<sup>53</sup>

Aging can have an impact on sexuality and sexual functioning. As with other organs, the reproductive and sexual organs lose efficiency. Women usually begin to have vaginal dryness and oftentimes males have difficulty with erectile dysfunction. We do not discuss sexuality enough when considering the lives of older adults. It is easy to assume that aging brings dramatic changes and that sexuality is not a topic that concerns older adults to any great degree. Sometimes, however, events bring about a dramatic shift in awareness and understanding. The boom in Viagra prescriptions is an example of such an event.

# 3.2.4. FREQUENTLY SEEN HEALTH CONDITIONS OF ADULTS WHO ARE ELDERLY AND/OR DISABLED

# <u>Arthritis</u>

Arthritis includes over 100 different diseases, including osteoarthritis, rheumatoid arthritis, gout, lupus, fibromyalgia, and many others.

Osteoarthritis is a disease that is caused by normal wear and tear on joints as well as trauma to the joints. In time, the cartilage inside the joint breaks down, and the bone surfaces inside the joint start rubbing together. The bone surface becomes rough, which causes bone damage and inflammation leading to further damage as bones rub together. Osteoarthritis is a degenerative condition and develops as we age because of the slowly occurring damage to the joints over time. Osteoarthritis occurs most frequently in the knees, hips, ankles, hands and other weight bearing joints.

**Symptoms:** Loss of movement, stiffness and swelling in the joints, snapping of the joints, bony growth at the joints and abnormal angulations.

**Treatment:** Medication such as acetaminophen, anti-inflammatory, and glucosamine; exercise, weight loss, nutrition, and hot soaks.

Resource Link: http://www.arthritis.org/

# **Asthma**

Asthma is an inflammatory disorder of the airways. An acute onset causes attacks of wheezing, shortness of breath, chest tightness, and coughing. When an attack occurs, the muscles surrounding the airways become tight and the lining of the air passages swell, thus causing a reduction of air that can pass by.

Asthma attacks can occur just occasionally, perhaps with exercise. Other individuals have more frequent episodes of shortness of breath, which can last for a few minutes or for days.

**Symptoms:** Coughing, shortness of breath, wheezing, or more serious symptoms such as bluish color to lips and face, sweating, decreased level of alertness, rapid pulse, and severe anxiety (due to shortness of breath).

**Treatment:** Long term and quick-relief medications, and hand-held inhaler.

Resource Link: http://www.mayoclinic.com/health/asthma/DS00021

From *Principles of Caregiving*, Aging and Physical Disabilities Module, Arizona Direct Care Curriculum Project, 2008.

# **Cancer**

Cancer is the uncontrolled growth of abnormal cells in the body. These cells are also called malignant cells

**Symptoms:** Symptoms depend on the location of the cancer. Lung cancer patients may exhibit coughing, shortness of breath, or chest pain. General cancer symptoms may include chills, fatigue, fever, loss of appetite, malaise, night sweats, and weight loss.

**Treatment:** Chemotherapy, radiation, surgery, medications.

Resource Link: http://www.cancer.org/docroot/home/index.asp

# **Chronic Obstructive Pulmonary Disease**

Chronic obstructive pulmonary disease (COPD) is a lung disease that makes it difficult to breathe. There are two forms of COPD: chronic bronchitis, which causes long-term swelling and excessive mucus in the airways in the lungs; emphysema, a disease that destroys the air sacs in the lungs.

**Symptoms:** Cough with mucus, fatigue, headaches, shortness of breath, wheezing, swelling of the ankles, feet, or legs, and frequent respiratory infections.

Treatment: Medication.

**Resource Link:** 

http://www.lungusa.org/site/apps/nlnet/content3.aspx?c=dvLUK9O0E&b=4294229&ct=3004005

### **Chronic Pain**

Chronic pain is a problem that many older adults assume they just have to live with and that nothing can be done. The barriers to adequate pain control are attitudes among both laypersons and professionals based on misinformation and fear. Chronic pain limits physical and social functioning and decreases quality of life. Case managers can assist their clients by helping them receive adequate treatment.

Pain is whatever the person experiencing the pain says it is. Pain is an unpleasant sensory experience and is an important protective mechanism. Acute pain is of relatively short duration with distinct onset and usually obvious pathology. This type of pain is a warning signal of possible tissue damage. Chronic pain lasts for more than six months or for one month after the expected healing period. Chronic pain may be intermittent or continuous and may vary in intensity. This pain is no longer a warning, but impairs long term functioning.

**Symptoms:** The perception of pain has two components: the sensory reception of pain which includes pain receptors, nerves, and conduction pathways to the central nervous system; and the interpretation of the sensory components, such as memory of past experiences, anxiety, and cultural influences on acceptance of pain.

**Treatment:** Pain medications.

Resource Link: http://www.ninds.nih.gov/disorders/chronic pain/chronic pain.htm

### **Diabetes**

Diabetes involves abnormally high levels of circulating glucose (blood sugar) in the blood that results from either too little insulin or inadequate insulin functioning. Glucose is the most important fuel source for our cells. Insulin, a hormone produced by the pancreas, stimulates the transport of glucose from the blood into the cells where it can be used or stored. The incidence of diabetes increases with age and contributes to a greater risk for heart disease, stroke, poor circulation, and kidney failure.

**Symptoms:** Excessive thirst, frequent urination, blurred vision, dramatic weight loss, weakness, slow healing wounds, nausea and vomiting.

**Treatment:** Oral medication, insulin injections, diet regimen, exercise and weight loss, and daily glucose monitoring.

Resource Link: <a href="http://www.diabetes.org">http://www.diabetes.org</a>

# Dysphagia:

Dysphagia is difficulty chewing or swallowing and/or painful swallowing. It can occur as the result of a stroke or cancer of the head or neck. Some individuals may be completely unable to swallow; others may have trouble tolerating liquids, foods, or saliva. Dysphagia occurs when there is a problem with any part of the swallowing process, such as weak tongue or cheek muscles, or the inability to start the swallowing reflex. Food is unable to be moved through the mouth to the stomach.

**Symptoms:** Difficulty trying to swallow, choking or breathing saliva into the lungs while swallowing, coughing while swallowing, regurgitating liquid through the nose, breathing in food while swallowing, weak voice, and weight loss.

**Treatment:** Surgery and or medication, possible diet texture modifications, tube feeding.

Resource Link: http://www.nidcd.nih.gov/health/voice/dysph.htm

### **Heart Disease**

The term "heart disease" covers a wide variety of heart conditions, including congestive heart failure, myocardial infarction (heart attack), arrhythmias, coronary artery disease (CAD), blockage of arteries, and angina. According to the Center for Disease Control and Prevention (2006), heart disease is the number one killer in the United States.

**Symptoms:** Symptoms of a heart attack may include chest discomfort, discomfort in other areas of upper body, shortness of breath, breaking out into a cold sweat, nausea and lightheadedness.

**Treatment:** Medications; diet and exercise.

Resource Link: <a href="http://www.americanheartassociation.org">http://www.americanheartassociation.org</a>

# **Stroke**

Strokes are the third leading cause of deaths in the United States, according to the Center for Disease Control and Prevention (2006). It is also a leading cause of disability. Stroke is a disease, which affects the blood vessels supplying blood to the brain. When a blood vessel bursts or is blocked, part of the brain does not receive the oxygen it needs. Brain cells in that area die quickly. The part of the body controlled by that part of the brain then cannot function correctly.

**Symptoms:** Sudden numbness or tingling, weakness in the face, arms or legs (especially on one side), confusion, trouble speaking or seeing, dizziness, loss of balance, difficulty walking, and sudden, severe headaches.

**Treatment:** Rehabilitation, medications.

Resource Link: http://www.strokeassociation.org/presenter.jhtml?identifier=1200037

### **HIV/AIDS**

HIV stands for human immunodeficiency virus. This is the virus that causes AIDS. HIV is different from most other viruses because it attacks the immune system. The immune system gives our bodies the ability to fight infections. HIV finds and destroys a type of white blood cell (T cells or CD4 cells) that the immune system must have to fight disease.

HIV/AIDS is no longer a disease of the young. Between 1991 and 1996, AIDS cases in the over-50 population rose more than twice as fast as those among younger adults. Older people with HIV/AIDS face a double stigma in our society today: ageism and infection with a sexually-or-IV-drug transmitted disease. Older adults with HIV/AIDS may face barriers in finding support from family, friends, church, community, etc. due to the stigma associated with the disease. When working with an older adult, it is important to assist him or her in overcoming the stereotypes of the disease. Something to keep in mind is that this information may be fairly new for older adults. Their generation did not grow up hearing about it; HIV/AIDS became known in the general public in the 1980's.

**Symptoms:** Individuals must be tested for the virus because symptoms may not appear for years. HIV/AIDS impairs the immune system, resulting in vague flu-like symptoms. These may include fever, rapid weight loss, sore throat, muscle and joint pain, rash and diarrhea.

**Treatment:** Antiretroviral therapy.

Resource Link: <a href="http://www.cdc.gov/hiv/resources/factsheets/">http://www.cdc.gov/hiv/resources/factsheets/</a>

### **Kidney Disease**

Chronic kidney disease is defined as having some type of kidney abnormality or "marker" such as protein in the urine, and having decreased kidney function for three months or longer. There are many causes of chronic kidney disease. The kidneys may be affected by diseases such as diabetes and high blood pressure. Some kidney conditions are inherited (run in families).

The kidneys are powerful chemical organs that perform the following functions: remove waste products from the body; remove drugs from the body; balance the body's fluids; release hormones and regulate blood pressure; control the production of red blood cells.

**Symptoms:** High blood pressure; blood and/or protein the urine; frequent urination; puffiness around eyes, swelling of hands and feet.

**Treatment:** Dialysis, kidney transplant.

Resource Link: http://www.kidney.org/kidneyDisease/

# 3.3. DISABILITIES

### 3.3.1. UNDERSTANDING DISABILITIES

Disabilities are often classified in two categories: developmental disabilities and acquired disabilities. Both categories of disabilities can result in substantial limitations in the following areas:

- Self-care and capacity for independent living
- Receptive and expressive language
- Mobility and self direction
- Learning and cognitive function
- Economic self sufficiency

**Developmental disabilities** begin any time during the development of the unborn child up to age 22 and usually last throughout the person's lifetime.<sup>54</sup> They include a number of severe chronic conditions that are due to mental and/or physical impairments, including the following:

- Cerebral palsy
- Autism spectrum disorder
- Intellectual disability, including Down's Syndrome, learning disabilities
- Epilepsy
- Neurological impairment

**Acquired disabilities** can occur at any time throughout one's lifetime; they can come about through injuries or illness and include conditions, such as:

- Multiple sclerosis (MS)
- Spinal cord injury (SCI)
- Traumatic brain injury (TBI)

We must ensure that individuals with disabilities and their loved ones have access to culturally competent services and support. These services are intended to assist the individual in reaching his or her maximum potential. Case managers play an important part in securing various elements of quality life for the individual with a disability: therapy, early intervention, education and training, and the opportunity for a quality life in the community.

# 3.3.2. OVERCOMING MYTHS AND STEREOTYPES

Many myths and stereotypes exist about those who have a developmental disability. Unless we examine our own beliefs about this population, the myths and stereotypes will influence the way we interact with clients. Case managers should ask themselves whether they believe any of the stereotypes and then adjust their thinking so that clients will be treated without bias. Attitudes and beliefs on the part of the lay population and professionals can get in the way of positive regard for the individual. Physical appearance or difficulties in communication may lead to the belief that a person is less intelligent, less credible, or less valuable. The following are some of the more common stereotypes and myths that we should examine.

<sup>&</sup>lt;sup>54</sup> Centers for Disease Control and Prevention, Developmental Disabilities, <a href="http://www.cdc.gov/ncbddd/dd/">http://www.cdc.gov/ncbddd/dd/</a>.

### **Caution! Myths and Stereotypes**

Many people have misperceptions about people who have a developmental disability. You may find **stereotypes and generalization**, for example, that people with a developmental disability

- are basically like children
- are inherently good and innocent
- are asexual
- lack control and restraint
- have sub-average intellectual capacity
- are incompetent and require a guardian
- are incapable of learning
- lack the capacity to control their emotions
- do not have the same feelings as other people
- deserve our pity.

Remember that such generalizations should be avoided. One cannot speak of people with developmental disabilities as if they are a homogenous population. Each person needs to be assessed and treated as a unique individual. All of the above statements disregard this important fact. Not all the statements are true for *all* people who have a developmental disability, but *some* statements may be true for *some individuals*.

- Centers for Disease Control and Prevention http://www.cdc.gov/ncbddd/dd/
- Arizona Division of Developmental Disabilities https://www.azdes.gov/main.aspx?menu=96&id=2454

# 3.3.3. OVERVIEW OF DISABILITIES

# **Cerebral Palsy**

Cerebral palsy is a type of developmental disability that causes damage to the brain. It may occur before, during, or after birth and results in the loss of control over voluntary muscles in the body. Activities such as sitting, standing, grasping, and eating are affected; it does not get worse over time.

Adaptive devices, including wheelchairs, walkers, specialized eating utensils and language boards, may help persons with cerebral palsy live more independently. It is important to remember that cerebral palsy may affect one part of the body more than another, and it can co-exist with other conditions, such as epilepsy or cognitive impairment.

**Treatment:** Cerebral palsy cannot be cured, but treatment will often improve the person's capabilities. This can include physical and occupational therapy, speech therapy, medications, sometimes surgery.

Resource Link: http://www.ninds.nih.gov/disorders/cerebral\_palsy/cerebral\_palsy.htm

# **Intellectual Disability (Cognitive impairment)**

Intellectual disability is a condition involving significant sub-average intellectual function and difficulty with activities of daily life, including communication, self-care, and participation in social situations. Intellectual disability is also called cognitive impairment and was formerly called mental retardation, a term that is now avoided. It is the most common developmental disorder, and it can start anytime before a child's 18<sup>th</sup> birthday. Some of the most common known causes of intellectual disability are Down syndrome, fetal alcohol syndrome, fragile X syndrome, and other genetic conditions, all of which occur before birth. Lack of oxygen during or after birth can be the cause, or serious head injury, stroke, or infections such as meningitis. Some of the more common characteristics found among those with an intellectual disability include: speech difficulties, shortened attention span, difficulties in eating, dressing, and other self-help skills and delays in motor development.

**Treatment:** There is no cure for intellectual disability, but many children can learn many things. Supporting services may include physical and occupational therapy, speech therapy, and special education.

Resource Link: http://www.nlm.nih.gov/medlineplus/developmentaldisabilities.html

### **Down Syndrome**

Down syndrome is a genetic condition that results from having an extra copy of chromosome 21. It is one of the most common developmental disabilities, with about 400,000 people in the United States having Down syndrome. The chance of having a baby with Down syndrome increases as parents get older. Symptoms can range from mild to severe, including mental and physical disabilities. People with Down syndrome may have other health problems, often affecting the heart, hearing, vision, and the digestive system. Persons with Down syndrome have a life expectancy of 60 years and will experience the normal process of aging. They have a higher than average likelihood of developing Alzheimer's disease.

**Treatment:** There is no cure for Down syndrome, but many children can go to school, and adults often lead productive lives and hold a job. Supporting services may include therapy and special education.

- http://www.marchofdimes.com/professionals/14332 1214.asp
- http://www.ndss.org/index.php (National Down Syndrome Society)

### **Epilepsy**

Epilepsy refers to a condition of the nervous system characterized by sudden seizures, muscle convulsions and partial or total loss of consciousness due to abnormal chemical-electrical discharges of the brain. Common behavioral characteristics that are related to epilepsy include drowsiness, fatigue, embarrassment, changes in emotion and alteration of a person's perception of familiarity or unfamiliarity. The primary characteristic of all types of epilepsy is the presence of seizures, Grand Mal and Petit Mal, lasting from a few seconds to a few minutes. Nearly 4 million people in the Unites States have some form of epilepsy.

**Treatment:** In the majority of cases, epilepsy can be controlled with anti-convulsive medication. People with epilepsy can learn to deal with seizures and recognize the triggers for seizures. Such things as lights and noise can precipitate seizures so that modification of a person's environment may be necessary.

Resource Link: <a href="http://www.epilepsyfoundation.org/">http://www.epilepsyfoundation.org/</a>

# **Multiple Sclerosis**

Multiple Sclerosis (MS) is a debilitating autoimmune disease in which the body's immune system attacks its own tissue and eats away at the protective sheath that covers the nerves. This interferes with the communication between the brain and body and may result in permanent nerve damage. Symptoms may include weakness or numbness in the limbs, impaired vision, tremors, tingling or pain in parts of the body, fatigue, and dizziness.

**Treatment:** Treatment focuses on combating the autoimmune response and managing symptoms with medications. Physical and occupational therapy is used to help preserve physical status.

Resource Link: http://www.mayoclinic.com/health/multiple-sclerosis/DS00188

### **Traumatic Brain Injury**

A traumatic brain injury (TBI) can occur when a sudden trauma causes damage to the brain. This can be the result of the head hitting a solid object, perhaps during a fall, or when an object pierces the skull and enters brain tissue. The symptoms may be mild to severe and the person may remain conscious or experience loss of consciousness. Other symptoms may include headache, dizziness, blurred vision, vomiting or nausea, convulsions or seizures, behavioral or mood changes, slurred speech, increased confusion, restlessness, or agitation.

Veterans returning from combat zones are increasingly diagnosed with traumatic brain injury. Ninety percent of these injuries are mild, but moderate and severe cases can result in life-long symptoms that interfere with daily life. During the Persian Gulf War in 1992, Congress created the Defense and Veterans Brain Injury Center (DVBIC) — originally known as the Defense and Veterans Head Injury Program (DVHIP) — to integrate specialized TBI care, research and education across military and veteran medical care systems. The website <a href="www.dvbic.org">www.dvbic.org</a> offers resources for active military, veterans, families, and providers.

**Treatment:** The treatment focuses on preventing further injury by insuring adequate oxygen supply to the brain and adequate blood flow and blood pressure. For severe cases, occupational, physical, and speech therapy may be provided.

- <a href="http://www.ninds.nih.gov/disorders/tbi/tbi.htm">http://www.ninds.nih.gov/disorders/tbi/tbi.htm</a>
- http://www.dvbic.org/

# Parkinson's Disease

Parkinson's disease is a motor system disorder that results from the loss of dopamine-producing brain cells. There are four primary symptoms that may become more pronounced: tremors in hands, arms, legs, jaw, and face; rigidity, or stiffness of the limbs and trunk; slowness of movement; and impaired balance and coordination. Progression of the disease may cause difficulty in swallowing, chewing, and speaking.

**Treatment:** Medications

Resource Link: http://www.ninds.nih.gov/disorders/parkinsons disease/parkinsons disease.htm

# **Spinal Cord Injury**

An injury to the spinal cord can result from a sudden traumatic blow to the spinal cord that fractures, dislocates, crushes or compresses one or more of the vertebrae. Injury can also result from a knife or gunshot wound that severs the spinal cord. An injury often causes permanent disability or loss of movement and sensation below the site of the injury. Symptoms following the injury may include severe back pain or neck pressure; weakness or paralysis in any part of the body; loss of bladder or bowel control; impaired breathing; numbness or loss of sensation in hands, fingers, feet or toes. Paralysis from a spinal cord injury may be referred to as: 1) Tetraplegia or Quadriplegia. This means the arms, truck, legs and pelvic organs are all affected. 2) Paraplegia. This means that all or part of the trunk, legs and pelvic organs are affected.

**Treatment:** Rehabilitation, medications, surgery

Resource Link: <a href="http://www.mayoclinic.com/health/spinal-cord-injury/DS00460">http://www.mayoclinic.com/health/spinal-cord-injury/DS00460</a>

# 3.4. COGNITIVE CHANGES IN OLDER ADULTS

### **General Behavioral Health**

The process of aging affects each person differently. However, there are several factors that influence the attitudes and behaviors of an individual, which can affect an older person's overall mental health. These factors are as follows:

- Personality
- Physical, mental and emotional health
- Intellectual functioning
- Economic and environmental limitations
- Family relationships
- Inner motivation

The most common mental disorders in older adults are, in rank order:

- 1) Depression
- 2) Suicide
- 3) Anxiety
- 4) Cognitive Impairment Dementia and Alzheimer's Disease

The Arizona Department of Health Services, Division of Behavioral Health, offers a 15-page publication on *Older Adults: Behavioral Health Prevention, Early Intervention, and Treatment*, which can be found at <a href="http://www.azdhs.gov/bhs/guidance/olderadult.pdf">http://www.azdhs.gov/bhs/guidance/olderadult.pdf</a>.

### **Depression**

Depression is the most common of all mental illnesses and is classified as a mood disorder; however, depression is <u>not</u> a normal part of aging. The development of depression in older adults is the result of a combination of biological, psychological, and social factors. Older individuals may experience a change in their self-concept plus a sense of loneliness and isolation as they transition through this phase of their life. These changes can lead to a feeling of increased dependence on family members or other caregivers, which in turn can cause a progressive emotional deterioration leading to the development of depression. It should be noted that the potential for suicide resulting from depression is high in the older adult population, especially in males.

The symptoms of depression in seniors may vary for each individual, but can include:

- A persistent sad, anxious, or "empty" mood
- Loss of interest or pleasure in ordinary activities, including sex
- Decreased energy, fatigue, or feeling "slowed down"
- Sleep problems (insomnia, oversleeping, early-morning waking)
- Eating problems (loss of appetite, weight loss, weight gain)
- Difficulty concentrating, remembering, or making decisions
- Feelings of guilt, worthlessness, or helplessness
- Thoughts of death or suicide; a suicide attempt
- Irritability
- Excessive crying
- Recurring aches and pains that don't respond to treatment

Treatment of depression takes place on three levels:

- Primary This is a prevention level concerned with promoting the health of the individual
  and decreasing the likelihood of the development of depression. An example of a
  primary treatment model of depression is a wellness group at a senior center, which
  focuses on basic exercise and nutrition information.
- Secondary This is the professional response to the person's expression of the symptoms of depression. It includes counseling and medication.
- Tertiary This treatment has a rehabilitative function to assist the person in the recovery process. An example of this level is a senior life skills group designed to teach coping skills in order to lessen the chance of the depression recurring.

Case managers working with older adults who suffer from depression play an important role. There are a number of things that the case manager can do to assist a person in getting back on the road to wellness. They are as follows:

- Providing opportunities for psychotherapy
- Encouraging regular exercise and a balanced diet
- Discussing self-care needs
- Offering invitations to support groups
- Encouraging socialization
- Providing opportunities for expression of feelings
- Assessing suicidal risk
- Monitoring and reinforcing positive coping behaviors
- Identifying support systems
- Providing family and caregiver support and education
- Ensuring that the person takes medication as prescribed

Depression can make a person feel tired, worthless, helpless, and hopeless. Case managers can help the person realize that these feelings are a part of the depression and are not the person's true situation. If available, family and friends should also assist the older adult by encouraging him/her to get treatment, and by offering emotional support, affection, and encouragement.

Resource Link: http://www.psychologyinfo.com/depression/seniors.htm

### Suicide

Older adults are disproportionately likely to commit suicide, with clinical depression often being the precursor. Most older persons who commit suicide will give warning signs. Some common signs are:

- Symptoms of depression
- Talking about death
- Giving away possessions
- Suddenly putting personal affairs in order
- Neglecting hygiene and self-care
- Stop taking medication and following diets
- Acquiring a weapon

If older adults should verbalize a desire to commit suicide, or should display any of the signs, **ALWAYS TAKE THEM SERIOUSLY**. There are many resources available to assist suicidal adults, such as crisis intervention agencies, crisis hotlines, support groups, psychiatric hospitals, or Adult Protective Services. Each individual agency will have its own protocol pertaining to suicidal individuals. However, a general overview in working with someone who exhibits signs is as follows:

- Be direct and factual when talking about suicide
- Implement suicide precautions if suicide is assessed to be imminent.
- Refer for treatment of depression with psychotherapy and/or medication.
- Realize that once the individual is serious about suicide, he/she remains at high risk despite being enrolled in therapy.
- Refer the individual for immediate professional mental health care as needed (in-patient if necessary).
- Remove potential method of self-injury.
- Assist the client in establishing effective support systems (if safe in their home).

Resource Link: Arizona Suicide Prevention Coalition <a href="http://www.azspc.org/">http://www.azspc.org/</a>

### **Anxiety**

Anxiety is the pathological counterpart of normal fear. It is manifested by disturbances of mood as well as thinking, behavior and physiological activity.

This can include panic disorder, agoraphobia, generalized anxiety disorder, phobias, obsessive-compulsive disorder, acute stress disorder, and post-traumatic disorder. These usually start younger in life. Generalized anxiety can include symptoms of muscle tension, easy fatigability, poor concentration, insomnia, and irritability.

**Resource Link:** Anxiety Disorders Association of America http://www.adaa.org/GettingHelp/AnxietyDisordersinOlderAdults.asp

# 3.5. DEMENTIA AND ALZHEIMER'S DISEASE

### **Dementia**

As the third most common mental disorder affecting older adults today, dementia influences an individual's ability to think, speak, reason, remember and move. There are several types of dementia, some of which are progressive and permanent, and some which can be treated and reversed. A number of different conditions can lead to the development of dementia. The three most common are vascular dementia, Lewy body dementia, and Alzheimer's disease.

<u>Vascular dementia</u>, also called multi-infarct dementia, results from an extensive narrowing and blockage of the arteries that supply blood to the brain or a stroke causing an interruption of blood to the brain. This type of dementia causes problems with thought, language, walking, bladder control, and vision. It is treatable.

<u>Lewy body dementia</u> occurs when Lewy bodies, microscopic protein deposits found in deteriorating nerve cells, exist on a widespread scale within the brain. This activity leads to symptoms affecting the individual's speed of thought, attention and concentration, and visual spatial abilities. It can also cause hallucinations and changes in the degree of alertness.

### Arizona Case Management Handbook

<u>Alzheimer's disease</u> is the most common form of dementia. It is thought to be responsible for 60-70% of all dementia cases. Alzheimer's is a progressive, degenerative, neurological disorder that attacks the brain and results in impaired thinking, memory, and behavior. It is caused by a loss of nerve cells in the areas of the brain that are vital to memory and other mental functions. This loss of cells is associated with the development of abnormal clumps (plaques) and tangles of protein in the brain. A brain afflicted with Alzheimer's also has a lowered level of chemicals responsible for carrying the messages back and forth between the brain cells.

A diagnosis of Alzheimer's disease should be sought as soon as possible. There are treatable health conditions that mimic dementia. Currently no single definitive test is available to identify Alzheimer's in a living individual. Confirmation of the disease requires an examination of brain tissue, which is done once the individual has passed on. Alzheimer's disease is progressive and ends in death. As the disease progresses, the individual moves through three different stages. Symptoms change as the stage changes.

# a) First Stage: 2 to 4 years leading up to and including probable diagnosis.

- Recent memory loss begins to affect job performance
- Inability to remember what the person was just told to do
- Confusion about places- gets lost on the way to work
- · Loss of spontaneity, the spark or zest for life
- Loss of initiative- can't start anything
- Mood/personality changes- individual becomes anxious about symptoms, avoids people
- Poor judgment- makes bad decisions
- Taking longer with routine chores
- Trouble handling money, paying bills

# b) Second Stage- 2 to 10 years after probable diagnosis (longest stage)

- Increasing memory loss and confusion
- Shorter attention span
- Problems recognizing close friends and/or family
- Repetitive statements and/or movements
- Restless, especially in late afternoon and at night
- Occasional muscle twitching or jerking
- Perceptual motor problems
- Difficulty organizing thoughts, thinking logically
- Not finding right words- makes up stories to fill in blanks
- Problems with reading, writing, numbers
- Being suspicious, irritable, fidgety, teary or silly
- Loss of impulse control-sloppy-won't bathe or afraid to bathe-trouble dressing
- Gains and then loses weight
- Seeing or hearing things that are not there
- Needing full time supervision

# c) Terminal Stage: 1 to 3 years

- Not recognizing family or image of self in mirror
- Loses weight even with a good diet
- Little capacity for self-care
- Inability to communicate with words
- May put everything in mouth or touch everything
- Inability to control bowels, bladder
- Possible seizures, difficulty swallowing, skin infections

There is currently no cure for Alzheimer's disease. Good planning, medical and social management, proper nutrition, exercise, and socialization can aid the individual, as well as the caregiver, in managing symptoms. There is only one FDA-approved drug currently being used to slow down the progression of the disease, Aricept.

#### Resource Links:

- The Mayo Clinic <a href="http://www.mayoclinic.com/health/dementia/DS01131">http://www.mayoclinic.com/health/dementia/DS01131</a>
- Medline Plus http://www.nlm.nih.gov/medlineplus/alzheimersdisease.html#cat5
- http://www.helpguide.org/elder/alzheimers dementias types.htm

# 3.6. ADDICTIONS AND OLDER ADULTS

# 3.6.1. SUBSTANCE ABUSE

Addiction is defined "as a chronic, relapsing brain disease that is characterized by compulsive drug seeking and use, despite harmful consequences." An individual who has formed an addiction to a substance has become dependent upon the substance. There are two types of dependence: psychological and physical. Psychological dependence involves the continual use of the substance despite significant problems in the individual's life caused by the substance use. When an individual continually puts a substance into the body, it adapts to that substance; it is used to receiving it and therefore develops a tolerance to the substance. When substance use ceases, withdrawal can provoke serious and life threatening illnesses and should always be done in a supervised medical facility. Some physical symptoms of withdrawal include headaches, diarrhea, sweating, physical pain, vomiting, and tremors.

### Alcohol

The largest problem with substance abuse comes from alcohol consumption and the interaction of alcohol with prescription and over-the-counter drugs. Community rates for "heavy alcohol use" range from 3-25% and from 2.2-9.6% for "alcohol abuse" depending on the population surveyed.

Because a number of the symptoms for alcoholism in older adults resemble other geriatric disorders, diagnosing alcoholism should be done only by a licensed professional trained in substance abuse and treatment.

The following is a list of some behavioral and medical indicators that an older adult may have a problem with alcohol:

- Cognitive decline or self-care deficits
- Non-adherence with medical appointments and treatment
- Unstable or poorly controlled hypertension
- Recurrent accidents, injuries or falls
- Frequent visits to the emergency room
- Gastrointestinal problems
- Unexpected delirium during hospitalization
- Estrangement from family

Resource Link: http://www.agingandaddiction.net/alcohol.html

<sup>&</sup>lt;sup>55</sup> National Institute on Drug Abuse, <a href="http://www.nida.nih.gov/scienceofaddiction/addiction.html">http://www.nida.nih.gov/scienceofaddiction/addiction.html</a>.

# **Prescription and Over-the Counter Medication**

The majority of older adults who misuse their medications do so unintentionally. Older individuals are often given multiple prescriptions from different physicians and they may not inform each physician of all medications they are taking. They may not read the labels correctly or they may misunderstand the dosage directions. For any of these reasons, overdose, additive effects, and adverse reactions from combining drugs can occur. Unintentional misuse can progress into abuse if the older adult continues to use the medication for the desirable effects that it produces, as any abuser of a drug does.

The following is a continuum of prescription drug use from proper use to dependence:

# **Proper Use**

- Taking medication as prescribed by doctor
- Correct dosage is prescribed
- Awareness of side effects

#### Misuse

- Dose level more or less than recommended
- Use for contraindicated purposes
- Use in conjunction with other medications with undesirable interactions
- Skipping doses/hoarding drugs/keeping expired medications
- Use with alcohol
- Sharing medications with others

### Abuse

- Use resulting in
  - Decline in work, home, volunteer performance
  - Legal problems
- Use in risky situations (e.g. driving while impaired)
- Continued use despite adverse social or interpersonal consequences

### Dependence

- Use resulting in
  - Tolerance
  - Withdrawal symptoms
  - Decline in normal activities
  - Unsuccessful attempts or a desire to cut down or control use
- Use of medication in larger amounts or for a longer period than was intended
- Use that includes a lot of time (including time to acquire and use the drug and to recover from its effects)
- Continued use despite knowledge that it has caused or aggravated a physical or psychological problem

Diagnosing any type of addiction to medication should be done only by a licensed professional trained in substance abuse and treatment.

Resource Links: http://www.agingandaddiction.net/

http://www.nlm.nih.gov/medlineplus/drugabuse.html#cat23

# **3.6.2. GAMBLING**

Gambling is defined as playing a game of chance for stakes. It occurs in different forms such as parimutuels (horse and dog tracks), lotteries, casinos, bookmaking (sports books and horse books), card rooms, and bingo. Pathological gambling is a "disorder of impulse control," as defined by the American Psychiatric Association. Older compulsive gamblers are driven to gamble in the same way that an addict needs his drug. It is a chronic and progressive disease, but can be diagnosed and treated.

There are three phases to the progression of gambling addiction.

- 1. <u>The Winning Phase</u>: Gamblers experience a big win or a series of wins that leaves them with unreasonable optimism that their winning will continue. Winning enhances their self-image. The older adult may daydream about gambling to escape reality and think that gambling is his or her most exciting activity. Some people feel great excitement when gambling.
- 2. <u>Losing Phase</u>: Self-esteem is jeopardized. Losses increase; the person begins bragging about past wins and may start gambling alone. To continue gambling, a person may borrow money legally or illegally, lie to family, friends, and spouses, or sell prized possessions. In some cases, individuals will mortgage property they own free and clear to cover increasing bets. They begin to "chase" bets, believing they must return as soon as possible to win back losses.
- 3. <u>Desperation Phase</u>: The gambler becomes obsessed with getting even to cover money lost through gambling. There may be increased health problems, severe mood swings, possibly crimes to get money. This phase can lead to suicidal thoughts, alcohol or other drug use, and emotional breakdown.

Most compulsive gamblers cannot admit a need for help until their life has become intolerable. Each individual must reach his or her own level of despair. There are a number of screening tools to assess for compulsive gambling. It is important to remember that this is an addiction, just like alcoholism and drug addiction. Only a licensed professional who is trained in substance abuse and treatment should diagnose a gambling addiction. The case manager's role is to refer and support, not diagnose.

- http://www.citizenlink.org/content/A000010957.cfm
- http://www.toomanybets.com/

# 3.7. COMMUNICATION

# 3.7.1. THE COMMUNICATION PROCESS

Communication in case management is the link between you, the client or caregiver, and the community. Communicating well with clients, family and providers improves the service delivery. For our purposes, "communication" refers to the person-to-person exchange of messages or information. In-person communication is both verbal and nonverbal.

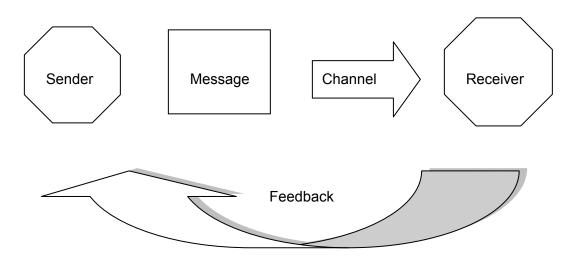
- 1. **Verbal communication** Verbal communication simply refers to the words we use; that is, what we say or write. Sign language and Braille are also verbal communication.
- 2. **Nonverbal Communication** Nonverbal communication accounts for most of the information we communicate, and tends to convey much information, such as our attitudes, emotions, expectations, and values. Nonverbal communication includes:
  - **How We Sound**: This refers to voice tone, inflection and volume, as well as speed of speech. This can also include attitudes or emotions, such as joy, fear, disapproval, or boredom.
  - Body Language: This refers to the use of our bodies to communicate information. Body language includes eye contact, facial expression (e.g., raised eyebrows), gestures (e.g. waving an open hand), touch, body posture (e.g., slouching), physical closeness to another person and spatial position (e.g., speaking from in front of, beside or behind the other person; speaking from above, below or at the same level as another person). Even one's appearance sends a message, be it clothing, jewelry, or things we carry in our hands.

# 3.7.2. WHY COMMUNICATION SKILLS ARE SO IMPORTANT

The purpose of communication is to get your message across to others. This process involves both the sender of the message and the receiver (see Illustration 3.1). This process leaves room for error, with messages often misinterpreted by one or more of the parties involved. A message is successful only when both the sender and the receiver perceive it in the same way. To do this, you must understand what your message is, what audience you are sending it to, and how it will be perceived. You must also consider the circumstances surrounding your communications, such as the situational and cultural context.

Effective communication happens when the intended meaning of the sender and the perceived meaning of the receiver are virtually the same. Often we take communication for granted; so it is important for case managers and other human services providers to be aware of the techniques for good communication. This involves knowing as much as possible about the person for whom the message is intended and being aware of possible communication problems. Asking for feedback from the other person can also help clarify whether your message was understood.

Illustration 3.1: The Communication Process



# 3.7.3. COMMON BARRIERS TO COMMUNICATION

When we communicate, we put information into code: our words, voice quality, and body language. The other person needs to decode the message in order to understand it. Communication barriers can popup at every stage of the communication process. Common barriers to communication include the following:

- 1. **Not listening.** If we don't receive the message, we cannot decode it.
- 2. Incorrectly interpreting what is said. This can happen when two people have different "code books," perhaps because they have different family customs or different life experiences, or because they are from different cultural groups. The ages of the people trying to communicate may be a factor in misinterpretation, as well as physical, economic, social, cultural, and psychological factors.
- 3. **Focusing on yourself.** Discussing your own problems or concerns can detract from the need to focus on a task or on the client.
- 4. **Not saying what is meant.** Fear of confrontation or trying to be sarcastic may cause us to formulate messages in a way that results in miscommunication.
- 5. **Using put-down messages.** Critical or angry messages are easy to recognize and avoid; however, we should also avoid communication that is insincere or patronizing.
  - Ordering, directing, commanding ("Do it this instant")
  - Threatening, Warning ("If you do that, I'll...")
  - Moralizing, preaching ("It's not right to say that.")
  - Lecturing ("It doesn't make sense to feel that way.")
  - Advising, giving solutions ("What you should do is....")
  - Judging, criticizing, and blaming ("It's your fault." "You're rude.")
  - Praising or agreeing that is patronizing, phony or grossly conflicts with the other person's expectations or beliefs.
  - Name-calling, ridiculing, shaming ("Shame on you!" "You will never get that done.")
  - Interpreting, diagnosing, and analyzing ("You just want attention.")
  - Probing, interrogating (Getting information so you can solve the person's problems for him or her.)
  - Withdrawing, distracting, and humoring ("Your problem reminds me of the joke about...")

# 3.7.4. USEFUL COMMUNICATION TECHNIQUES

### **Assertive Communication**

Assertiveness is the ability to say what you want to say but still respect the rights of others. Being assertive means being clear and honest when expressing feelings and opinions. It is respectful of both the sender and the receiver of the message. When we use assertive communication, we avoid the aggressive language of put-downs and defensiveness. We also stop short of passive communication, which may cause us to withhold information or give in too easily.

# Messages that Destroy Communication<sup>56</sup>

- 1. <u>Solution Messages</u> take responsibility away from the other person and tend to put the person under external control.
- 2. <u>Judgment Messages</u> diminish self-worth and integrity of the other person.
- 3. <u>Denial Messages</u> get the other person away from the issue, joke about the strong feelings, and put the problem aside.

**Assertive communication** can be used to turn these counterproductive messages into effective communication. Examples:

Message Type	Speaker	Assertive Communication
Solution	'I will work this out for you and everything will be just fine."	"I wish I could promise everything will be ok, but I can't. Let's review the issues and options available to make sure we haven't missed anything."
Judgment	"You know this isn't good for you. I just don't know why you insist on this behavior."	"It appears you are consistent in the skipping of your insulin several times every week. Is there a reason I can help you with? What are some of the consequences of this if you choose to continue not to take your medication?"
Denial	"Oh yes, I'm aware you have cancer. Now let me see what is your income?"	"When your referral was called in, it was noted that you recently have been diagnosed with cancer." (Pause)(Income can wait until later if Client wants to share about his/her experience).

<sup>&</sup>lt;sup>56</sup> Oregon Senior and Disabled Services, 1990.

# **Person-First Language**

A very useful concept to guide our communication is *Person First Language*. Kathie Snow, who has written extensively about this, reminds us that words are powerful and that poorly chosen words can perpetuate negative stereotypes and create barriers.<sup>57</sup> A person with a disability is still a person – not a condition. The illness or disability is often just a small part of who they are. The basic principle of person-first language is to name the person first and only then to describe the disability or impairment.

Examples: Anna is a 5-year-old girl. She has autism.

Mr. Barnes uses a wheelchair.

People with disabilities (instead of: the disabled / the handicapped)

# Therapeutic Communication <sup>58</sup>

Good communication between the case manager and the client is important to provide services that meet the needs of the client. Therapeutic communication is a process designed to involve the individual in conversation that is beneficial to her or his physical or mental well-being. Useful techniques:

- Use open-ended comments to encourage verbalization. This keeps a person from just answering yes or no.
- Allow for the collection of more information to meet the person's needs.
- Use paraphrasing or reflective responses to clarify information (explained below). Use this
  method to direct the conversation to specifics.

### 1. Open-Ended Questions

Use open-ended questions to allow others to engage in the conversation and share information. It gives them the chance to tell you what is important to them.

- Closed-ended questions are answered by "yes" or "no"
  - Did you eat breakfast today?
  - o Are you feeling okay?
- Open-ended questions are responded to with more details
  - O What did you have for breakfast today?
  - Could you describe how you are feeling today?

# 2. I - Messages

Use "I" messages instead of "You" messages. You-messages can put the blame on the others, but an I-message is assertive. It lets the speaker take responsibility for his/her own feelings.

- You message
  - You make me worry when you don't talk to me.
- I message
  - o I worry when I cannot communicate with you.

<sup>&</sup>lt;sup>57</sup> www.Disabilityisnatural.com is a website with articles and information on thinking about disabilities, hosted by Kathie Snow.

<sup>&</sup>lt;sup>58</sup> Adapted from *Principles of Caregiving*, Arizona Direct Care Curriculum, 2008.

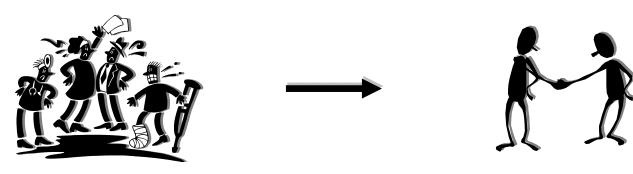
### 3. Reflective Responses

Using reflective responses can help the speaker clarify his or her own meanings. You can use several specific techniques.

- Restate what the speaker has said.
  - So you think that you don't get enough sleep.
- Pay attention to feelings.
  - It seems you are upset about this.
- Do not guide the conversation and do not make suggestions.
  - Don't say: Perhaps you should...

### **Conflict Resolution**

- 1. Use listening skills and therapeutic communication techniques listed above.
- 2. Listen intently to let the person know that what he/she has to say is very important.
- 3. If the person knows that what he/she has to say has value, he/she will begin to diffuse anger.
- 4. Do not respond with anger or become defensive.
- 5. Empathize. See it from the other person's perspective.
- 6. Then, once the person sees you are an ally, not an enemy, fill him/her in on your challenges, feelings, roadblocks, and/or perspective.
- 7. Put your own emotions on hold. Take a few minutes of "time-out" if needed to diffuse anger and gather your thoughts.



### **Guidelines for Active Listening**

- Stop talking. You cannot talk and listen at the same time.
- Stop all other activity. Focus on the speaker.
- Put your conversation partner at ease.
- Help the other person feel he/she is free to talk. Create an environment conducive to good communication.
- Show the other person that you want to listen. Look and sound interested.
- Look and act interested. Use body language and your tone of voice to express your enthusiasm.
- Do not jump to conclusions. Hold your temper.
- Avoid making assumptions about what the other person is going to say or completing his/her sentences for them.
- Empathize with the speaker. Try to understand the other person's motivation. Put yourself in his/her situation.
- Be patient. Allow plenty of time. Do not interrupt the other person. Even a long pause does not mean the speaker is through.
- The only argument you can ever "win" is the one you avoid. If you win and the other person loses, you lose.
- Ask questions. This encourages the speaker and shows your active interest. Questions also direct the conversation.
- Verify. Reiterate the information back to the speaker to check for accuracy. Paraphrase, never mimic.

# 3.7.5. COMMUNICATION WITH CLIENTS WITH IMPAIRMENTS

Beyond being mindful of good communication generally, case managers can learn about techniques for communicating effectively with clients who may have a sensory impairment.

# **General communication techniques:**

- 1. Stop talking or doing something else and pay close attention.
- 2. Be patient. Do not interrupt or rush the person.
- 3. Pay attention to both the words and nonverbal communication. From the nonverbal communication, you can pick up the emotional message and signs of physical discomfort, lagging attention, and vision or hearing problems.
- 4. If you do not understand, it may be best simply to say so.

# Special issues in communicating with persons who have a hearing and visual impairment

### Some Principles of Sensory Loss

- All five senses tend to decline gradually throughout adulthood.
- The type and degree of sensory loss varies between individuals.
- It is more difficult to cope with multiple losses than a single loss.
- People consciously and unconsciously develop ways to compensate for sensory losses.
- You will be more effective in your work if you know and respond to a person's sensory abilities and limitations.
- Don't be over-protective to a person with a hearing or visual impairment.

### **Indicators of Hearing and Visual Impairment**

Persons who are suffering from hearing loss may exhibit some or all of the following behaviors.

- Leaning closer to the speaker.
- Cupping an ear.
- Speaking in a loud voice.
- Not speaking clearly.
- Turning their "good" ear toward you.
- Asking for things to be repeated.
- Answering questions inappropriately.
- Give blank looks.
- Show inattentiveness or signs of losing interest.
- Refuse to engage in conversation.
- Show a lack of reaction.
- Display emotional upset—perhaps anger.

Visual changes vary even more between older people than hearing changes. Older adults who have vision problems may exhibit some of the same behaviors as those with hearing loss. They may also:

- Squint, frown, or grimace during conversation.
- Rely more on touching.
- Give inaccurate descriptions of detail or colors.
- Display a lack of eye contact.
- Appear to be more distrusting and/or withdrawn,
- Seem to be more worried about awkwardness.
- Exhibit a reluctance to communicate.
- Appear to be fearful of even normal activity.

# Communicating more effectively with persons who have a hearing and visual impairment

Techniques for communicating more effectively with the hearing and visually impaired include the following:

- Be sure you have the person's attention before speaking. Be careful not to startle the person.
- Slow down, yet speak at a natural pace. Give additional time for the person to respond.
- Tell the person if you move around or leave the room.
- Position yourself directly in front of the person when you converse. Adjust your distance from the person depending on whether he/she sees better close up or farther away.
- If possible, position yourself so that there is a plain background for you (e.g., a plain wall instead of a bookcase).
- Pronounce your words clearly. Do not mumble; yet do not exaggerate words or sounds. Do not speak one word at a time.
- Try lowering the pitch of your voice instead of increasing your volume. If you raise the volume of your speech, do not shout or raise the pitch of your voice.
- Use gestures and objects to clarify what are you saying.
- Be especially careful that lighting is appropriate.
  - > Arrange for a higher than usual level of light from several, non-glare sources.
  - > Be sure that lighting is glare-free and shadow-free.
  - ➤ Be certain that lights and windows are behind the elderly person rather than behind you so that your face is not in shadow

### Communicating with a person who has dementia

Useful suggestions for communicating effectively with persons who have dementia include:

- 1. Be calm and supportive. Move and talk slowly and gently.
- 2. Do not expect logical or rational communication. Avoid arguing about facts, since the only result is likely to be bad feelings and problem behaviors.
- 3. Pay attention and respond to the emotions the person is showing.
- 4. Use short sentences with the important information at the end of the sentence. For example, "Do you want day care one or two days per week?"
- 5. Use closed-ended questions ("Do you want coffee or tea?") instead of open-ended questions ("What do you want to drink?")
- 6. If the person does not understand what you are saying, repeat, and then revise using different words. ("Do you want to rest?" → "Do you want a nap?")
- 7. Use proper names ("Jane") and nouns ("chair"), instead of pronouns ("she", "it").
- 8. Enlist the help of family, friends, or neighbors.
- 9. Contact a protective services agency, aging ombudsman or area agency on aging if the person has no one to help him/her.
- 10. Be aware of language barriers.

# 3.7.6. GUIDE TO WHEELCHAIR ETIQUETTE

- Ask Permission Always ask the person if he or she would like assistance before you help. It may be
  necessary for the person to give you some instructions. An unexpected push could throw the person off
  balance
- <u>Be respectful</u> A person's wheelchair is part of his or her body space and should be treated with respect. Don't hang or lean on it unless you have the person's permission. When a person transfers out of the wheelchair to a chair, toilet, car, or other object, do not move the wheelchair out of reaching distance
- Speak Directly Be careful not to exclude the person from conversations. Speak directly to the person and if the conversation lasts more than a few minutes, sit down or kneel to get yourself on the same plane as the person in the wheelchair. Also, don't be tempted to pat a person in a wheelchair on the head, as it is a degrading gesture.
- <u>Give Clear Instruction</u> When giving instructions to a person in a wheelchair, be sure to include distance, weather conditions, and physical obstacles, which may hinder their travel.
- Act Naturally It is okay to use expressions like "running along" when speaking to a person in a wheelchair. It is likely the person expresses things the same way.
- Wheelchair Use Does not Mean Confinement Be aware that persons who use wheelchairs are not confined to them.
- Questions Are Okay It is all right for children (or adults) to ask questions about wheelchairs and
  disabilities. Children have a natural curiosity that needs to be satisfied so they do not develop fearful or
  misleading attitudes. Most people are not offended by questions people ask about their disabilities or
  wheelchairs.
- Some Persons Who Use a Wheelchair for Mobility Can Walk Be aware of the person's capabilities. Some persons can walk with aids, such as braces, walkers, or crutches, and use wheelchairs some of the time to conserve energy and move about more quickly.
- Persons Who Use a Wheelchair for Mobility Are Not Sick Don't classify persons who use
  wheelchairs as sick. Although wheelchairs are often associated with hospitals, they are used for a
  variety of non-contagious disabilities.
- Relationships Are Important Remember that persons in wheelchairs can enjoy fulfilling relationships which may develop into marriage and family. They have physical needs like everyone else.
- Wheelchair Use Provides Freedom Don't assume that using a wheelchair is in itself a tragedy. It is a
  means of freedom, which allows the person to move about independently. Structural barriers in public
  places create some inconveniences; however, more and more public areas are becoming wheelchair
  accessible.

# 3.8. CULTURE

# 3.8.1. CULTURALLY SENSITIVE CASE MANAGEMENT

The concept of culturally sensitive case management is essential. Cultural norms and standards are deeply ingrained in individuals and in society as a whole. Case managers will be called upon to assist people from diverse cultural groups. Problems are at times inevitable when persons from two different cultural backgrounds with conflicting values meet. Ideally, a common ground should be reached so that the parties can proceed in their work together. Interventions and approaches that are culturally relevant and sensitive will greatly reduce stress and conflict.

If you find yourself having negative thoughts about the things your clients believe in and the way they live, consider cultural differences as one of the sources. You must be sensitive to your own culturally driven behaviors and attitudes and be able to adapt your approach accordingly.

### Culturally sensitive casework includes an understanding of:

- language differences and the meaning of words
- diet and food habits
- acceptable ways of dressing
- social patterns of behavior
- religious customs, rituals, taboos
- nonverbal communication
- beliefs about destiny and personal responsibility
- attitudes toward health and illness
- appropriate male/female roles
- attitudes towards authority
- work orientation
- family and interpersonal relationships
- ethics
- use of time and space
- economic systems

### **Cultural Diversity and Health**

Case managers need to know that people have different views of health and illness depending on their background and upbringing. This can affect how individuals feel about receiving help from others. Some prefer family members to provide assistance; others have strong preferences about working only with a male or female practitioner. There are also different views of dealing with illness or disability.

Here are some examples of different perspectives:

- Traditional remedies vs. modern medicine and technology
- Aggressive treatment vs. gentle, mild treatments
- Acceptance (a wait-and-see approach) vs. taking action

# What is meant by culture?

Culture is a broad term that refers to the totality of the beliefs, values, social interactions and practices taken as an integrated whole which distinguishes one group or society from another. People often associate culture with a certain country or geographic region, and they may think of foods, dress, and festivals as the things that define a culture. Societies tend to have certain cultural characteristics – we can make broad statements about Americans, Chinese, or Italians – but there are many other types of groups that can develop a culture. Organizations tend to develop a culture, be they large companies or small non-profit organizations. Young people have a different culture than older adults, and religious or professional groups may develop a certain culture. When we speak of countries or societies, the term ethnicity or ethno-cultural can be used to designate characteristics associated with such a group. However, it is important to remember that within any large group – be it a country, a region, a church, or the government – there are many variations and sub-groups or sub-cultures.

# What is ethnicity?

Ethnicity refers to the values, perceptions, feelings, assumptions, and customs associated with ethnic group affiliation or membership. Ethnic identification commonly develops through contacts with family, friends, and persons in one's neighborhood with whom one associates and lives. Ancestry is often a component of ethnicity, and large ethnic groups in the United States are African American, Irish Americans, or Latinos. By one estimate, there are 150 different ethnic groups in the United States, <sup>59</sup> not including the more than 200 Native American tribes. Ethnic groups usually share a common culture, but it is not a valid assumption that all members of any ethnic group are culturally identical. Ethnicity and culture are interrelated, and some researchers emphasize the importance of **ethnocultural competence** for human and social services. <sup>60</sup>

A person's behavior is determined by cultural influences as well as by personal characteristics. When we think of the Egyptians, Athenians, members of various Native American nations, contemporary Americans, Mexicans, Chinese or Nigerians, we associate particular cultural attributes and behaviors to each group. We may think of particular behaviors, foods, or attire; however, some of these may be stereotypes. Not all members of a certain culture are the same: there are sub-groups within any culture, and factors such as age, gender, or education will determine some differences.

Cultural and ethnic influences can also be very subtle and invisible. People are often unaware of their presence. As children, we are exposed to the values, attitudes, roles, and behaviors acceptable to and expected by the cultural group within which we are being raised. An example: An American child seated at the dinner table reaches for the salt and pepper. The child is told by the parent that reaching is not polite and to ask that the salt and pepper be passed. An Afghan child seated at the dinner table asks his mother to pass the salt and pepper. The father reprimands the child and says, "Don't you have hands? Don't bother your mother. Reach for what you want." The Afghan child, seated at an American dinner table, reaching for everything, might be looked at as ill mannered. In his/her own culture, however, the behavior is quite acceptable. Every culture defines the relationships and roles that people assume as members of that society. To understand how different those definitions can be we need only think of the roles of the male and female in the United States as opposed to those same roles in Saudi Arabia or Japan.

http://pubs.niaaa.nih.gov/publications/Social/Module10HEthnicity&Culture/Module10H.html.

<sup>&</sup>lt;sup>59</sup> Wikipedia lists approximately 150 ethnic groups at <a href="http://en.wikipedia.org/wiki/Category:Ethnic groups in the United States">http://en.wikipedia.org/wiki/Category:Ethnic groups in the United States</a>.

<sup>60</sup> National Institute on Alcohol Abuse and Alcoholism,

#### What are values?

Values are used by groups of people or cultures as guides or criteria for selecting good and desirable behaviors. Values differ greatly among and within groups of people. Examples of common values include physical beauty, self-discipline, work ethic, punctuality, cleanliness, independence, and individuality. Values influence the way we look at other people. For example, you may label a client who has a messy house as lazy because you value tidiness and cleanliness. If you value the work ethic, you may feel that an unemployed person is a failure. It is important that you know what your values are. As a case manager, you must be non-judgmental about other people's values especially when they are different from yours.

### What are norms?

Norms are the rules by which human behavior is governed: "the way we do things here." Norms flow from the cultural values of the group involved. Dress codes are typically a recognizable norm. Employees of a financial institution may be wearing conservative clothing, such as business suits, whereas employees of a small information technology firm may be comfortable in jeans. Many values are universal, such as helping others, honoring one's elders, or being modest. How these translate into norms and behaviors can result in substantive differences. Helping others to improve their health and well-being is a widespread value in many cultures; however, how that help is delivered can vary significantly. For example, in the United States the individual needing assistance (the client or patient) has the right to self-determination and personal preferences. In other cultures, the family may have a say in the decision about treatments and services. When families bring their values and norms to the United States, there may be a conflict between the family's preferences and "how things are done here." Not uncommonly, conflicts develop within families when, for example, children of immigrant families adapt to the norms of the American culture in their community.

### 3.8.2. DIFFERENT CULTURES IN ARIZONA

Arizona is a good example of a state with many cultures and ethnic groups. The U.S. Census Bureau breaks down the Arizona population by self-reported categories of race as follows:

Illustration 3.2.: Arizona Demographics

White persons, percent, 2008	86.5%
Black persons, percent, 2008	
American Indian and Alaska Native persons, percent, 2008	
Asian persons, percent, 2008	
Native Hawaiian and Other Pacific Islander, percent, 2008	
Persons reporting two or more races, percent, 2008	
Persons of Hispanic or Latino origin, percent, 2008	
White persons not Hispanic, percent, 2008	
Foreign born persons, percent, 2000	
Language other than English spoken at home, percent, age 5+, 2000	

Source: http://quickfacts.census.gov/qfd/states/04000.html

Case managers may work with clients and families from a number of different backgrounds. There are too many to describe here. The following section provides basic information for case managers on refugee groups and two of the larger ethnocultural groups in the state, Native Americans and Hispanics. Please keep in mind that such a brief overview by necessity simplifies and generalizes.

# Refugees in Arizona

Under United States law, a refugee is a person who is outside his or her country of origin and is unable or unwilling to return due to persecution, or a well-founded fear of persecution, based upon:

- Race
- Religion
- Nationality
- Political opinion
- Membership to a particular social group

This definition of a refugee does not include:

- Economic migrants
- Asylum seekers
- Persons displaced by natural disasters
- Internally displaced persons (IDPs)

Refugees applying for resettlement in another country undergo rigorous screening (medical and security), interviews and cultural orientation before they leave their country. This process can take anywhere from a few months to several years to complete.

Refugees who have been resettled in Arizona are mostly from these locations:

- Iraq
- Bhutan
- Somalia
- Burundi
- Cuba

Far from homogenous, **Iraqi** refugees represent a variety of ethnic and religious groups. They tend to have more professional experience, formal education and higher language proficiency than other groups, but many still arrive with no experience, training or knowledge of English. Some common challenges for new Iraqi arrivals include:

- Adjustment to living in poverty
- Securing employment
- Learning the language
- Transportation
- Navigating the healthcare system and other government bureaucracies
- Adapting to American culture (for example, the concepts of time, individualism, or the status of women)
- Physical health war-related injuries
- Mental health high incidence of depression, anxiety and Post-Traumatic Stress Disorder (PTSD)

The majority of **Bhutanese** refugees are ethnic Nepalis. In the 1990s, they were stripped of their Bhutanese citizenship and legal rights and subsequently expelled from their country after the Bhutanese government implemented a series of policies aimed at unifying Bhutan under the Druk culture, religion and language. Most Bhutanese refugees have spent over 10 years in refugee camps. Resettlement challenges:

- Very few newly arriving refugees understand the English language
- Limited exposure to modern amenities
- Caste system

Resettlement Strengths

- Thriving Bhutanese community in Arizona
- General desire to work their way up the system

The **Somali-Bantus** and **Burundians** constitute distinct ethnic minorities in Africa and have been victims of war, persecution and government-instituted discrimination throughout their history. Most Somali-Bantu refugees arriving in the United States have spent the majority of their lives in refugee camps. The Burundian refugees have been living in camps in Tanzania since 1972. They fled from government sponsored ethnic cleansing in 1972 and again in 1993. Resettlement challenges:

- Most have spent their entire lives in refugee camps, with extremely limited exposure to modern amenities, access to education, and employment outside the home
- Very limited knowledge of English
- Racial discrimination in the United States
- "Fight or flight" mentality (survival mechanisms developed from years in refugee camps) Resettlement strengths:
  - Strong communal ties and support networks
  - Refugee children often assume additional responsibilities in their families acting as educators, interpreters, caregivers, etc.

**Cuban** entrants have been coming to the United States in waves since the 1950s. Resettlement challenges:

• Value clash – American social services (health care, education, etc.) may be frustrating and appear inefficient to Cubans, who are accustomed to a socialist system

# Resettlement strengths:

- Cubans in Arizona may find comfort and support in the wider community of Spanishspeaking residents (however, this may serve as a disincentive to learn English)
- Education is highly valued

# Native American Culture 61

Cultural diversity challenges health practitioners and educators to become aware of the clients' health beliefs, attitudes and values. It is necessary to understand the Native American's perceptions of health and illness and understand their health customs and practices. Arizona is home to 22 tribes, with over 250,000 Native Americans in the state. 62 It is important to remember that not all tribes are the same and that Native American cultures are very complex.

The twenty-two tribes, nations, and communities of Arizona are:

- Ak-Chin Indian Community
- Navajo Nation
- Cocopah Tribe
- Pascua Yaqui Tribe
- Colorado River Indian Tribes
- Salt River Pima-Maricopa Indian Community
- Fort McDowell Yavapai Nation
- San Carlos Apache Tribe
- Fort Mojave Indian Tribe
- San Juan Southern Paiute
- Fort Yuma-Quechan Tribe

<sup>&</sup>lt;sup>61</sup> Adapted from multiple resources, including Shelton, Brett Lee, *Legal and Historical Roots of Health Care for American Indians and Alaska Natives in the United States,* pps 1-5, Feb., 2004; Kunitz SJ, Levy JE. *Navajos*. In: Harwood A, ed. *Ethnicity and Medical Care*. Cambridge, Mass: Harvard University Press; 1981; and University of Washington Medical Center, "Communicating with Your American Indian/Alaska Native Patient", April 2007.

<sup>&</sup>lt;sup>62</sup> "Arizona's Native American Tribes," Economic Development Research Program, University of Arizona, <a href="http://edrp.arid.arizona.edu/tribes.html">http://edrp.arid.arizona.edu/tribes.html</a>.

- Tohono O'Odham Nation
- Gila River Indian Community
- Tonto Apache Tribe
- Havasupai Tribe
- White Mountain Apache Tribe
- Hopi Tribe
- Yavapai-Apache Nation
- Hualapai Tribe
- Yavapai-Prescott Indian Tribe
- Kaibab-Paiute Tribe
- Zuni Tribe

### Resource links:

- Phoenix Area Indian Health Service
   http://www.ihs.gov/FacilitiesServices/areaOffices/Phoenix/phx\_culture.cfm
- University of Arizona http://edrp.arid.arizona.edu/tribes.html
- Native Languages of the Americas <u>www.native-languages.org/arizona.htm</u>

### History

Tribal sovereignty is the principle that Native Americans have inherent rights to be governed by their own laws – to the exclusion of state and local but not federal authority. Traditional Indian healthcare practices exist within a complex legal and historical framework.

### **Basic Beliefs**

There are over 565 federally recognized tribes and more than 100 state recognized tribes. These tribes once lived on federal reservations and in small rural communities, and now large numbers live in large metropolitan areas. In spite of these changes, these tribes generally share a spiritual attachment to the land, the desire to share with others, a lack of materialism, a belief in a supernatural power residing in all objects, both animate and inanimate; and a determination to retain the culture.

The Navajo (or, Dine), for example, respect and honor nature and "the Holy Ones" (supernatural deities on which humans depend physically and spiritually, such as earth, the sky, mountains, water, animals, and plants). They believe that life should always be in harmony with the immediate surroundings. The central belief system is a blueprint and central focus for all aspects of living (hozho), which translates as a holistic view of harmony, balance, and peace.

### **Traditional Foods**

For many of the tribes, food has great religious and social significance. Hospitality, considered a serious obligation, includes the serving of food. Common foods may be prepared and used in different ways from region to region. Fry bread is traditional for many Indians and is eaten with many foods, including mutton stew, corn soup, fish chowder, and beans. Corn, another traditional food is added to soups and stews, ground to form a thickener for stews and drinks, and to produce cornmeal for breads, and treated with lye to make hominy.

# Language

Another important cultural variable is the ability to speak and understand English, even for younger Native Americans. English may be used as a second language. Navajo, for example, is traditionally an oral, not a written language. The Navajo language always reflects the concrete over the abstract and conceptual as compared to the English language. Languages may be further complicated because of variations within the Tribal group. For example, there are three dialects within the Hopi Nation and six in the Tohono O'odham Nation.

### **Health and Healing Practices**

In many of the Native American cultures, health is perceived as a state in which the entire being — mind, body, and spirit — is in balance. Illness is a result of disharmony or imbalance. Throughout history, Native Americans have relied on practitioners of traditional medicine, medicine men and women, herbalists, and shamans. There are tribes that continue to rely on traditional medicines, healing and purifying ceremonies, teas, herbs, special foods, and therapeutic signs. Many Navajos, for example, use a combination of treatments, which may include traditional ceremonies, Western medicine, Christian ministers, and healers from neighboring tribes. For instance, tribal members may use a sweat bath with prayers and songs to be cleansed spiritually and physically.

Cultural assessment of the patient is an important step in identifying the patient's views and beliefs related to health and illness. Beliefs about the cause, prevention, and treatment of illness vary among cultures. Native Americans are modest and value privacy and confidentiality. An outsider, who has not established rapport with the patient and family, and, perhaps, the community, may not be admitted to the home. This may include unfamiliar home health aides, Public Health Nurses, Community Health Representatives, or representatives from outside agencies (e.g. Physical Therapists, medical equipment deliverers, or insurance, Medicaid or Medicare case managers). Permission should be asked before touching, and explanations for examinations and questions should be given in a quiet, calm manner.

#### **Time Orientation**

Time orientation may be perceived as cyclical and as present time in the moment as compared to the linear, future-oriented time associated with Western culture. Example: Appointments are best scheduled within a window of time to allow for flexibility.

### **Family and Community**

The concept of family may include immediate and extended family as well as community and tribal members. Important decisions such as medical decisions may involve the entire family based on its impact on the group. Tribal members may be reluctant to sign documents and consider verbal agreements as sufficient.

### Communication

Nonverbal: Direct eye contact may be avoided out of respect or concern for soul loss or theft; pain may not be expressed directly but as "feeling" uncomfortable or expressed as a story; silence may be used to maintain harmony, or as a way to be non-confrontational. Example: A period of two minutes may pass without dialogue, and several periods of silence may occur before trust is established.

Verbal: Communication can be enhanced by building a relationship first, before asking direct questions. Storytelling and circular conversation may be used to build trust or describe symptoms. For example, a story about an ill neighbor may be a metaphor for having the same symptoms. Interrupting a speaker may be considered rude.

Touching: Touch may be thought to be very personal, and head and hair may be considered particularly sacred.

# Hispanic Culture<sup>63</sup>

The Hispanic American community has origins in Cuba, Central and South America, Puerto Rico, and other Spanish speaking countries. These cultures have Indian, European, and African roots, which make them very racially and culturally diverse. The Hispanic culture has unwritten rules that govern social interactions and affect the way individuals perceive, seek, and receive services. For example, the culture, politics, food and music of Mexican Americans are very different from those of Cuban Americans.

#### Resource Links:

"The Hispanic American Community," Transcultural Nursing, <a href="www.culturediversity.org/hisp.htm">www.culturediversity.org/hisp.htm</a> The Provider's Guide to Quality and Culture, <a href="www.erc.msh.org">www.erc.msh.org</a>

#### **Basic Beliefs**

Common cultural characteristics for Hispanics in the United States include family, respect, trust, and spirit.

# **Family**

Hispanic families traditionally value interdependence over independence and cooperation over competition. Hispanics include many people in their extended family such as aunts, uncles, cousins, close friends, and godparents. They are viewed as a primary source of support, may accompany each other to appointments, and are involved in important decision-making. Individuals may tend to rely on their family for help and support rather than professionals. The eldest male is considered the authority figure and gender roles are traditional. It is common for family members to share a residence and for children to live with the parents until they marry.

### Respect

Elders and authority figures are addressed formally and given special consideration and respect. One way to show respect is to avoid eye contact with authority figures. Social relationships are generally warm, friendly and affectionate, and are based on politeness and respect with avoidance of confrontation and criticism. Personal space is close. Modesty and privacy are important. Overt disagreement is not considered to be appropriate behavior. For example, case managers may consider asking questions about alcohol use, mental problems, violence, or stressors in an indirect way, ensuring privacy.

### **Trust**

It may take time to establish trust. One way to accomplish this is by expressing respect for the culture and taking an interest in the person. Once trust is established, Hispanics will value the time spent together.

### **Time Orientation**

A hurried pace may not be considered acceptable to some Hispanics. Social occasions may start later than expected. Time and punctuality are often flexible.

### Health

The Hispanic culture looks at health from a synergistic point of view, and health is expressed as the continuum of body, mind, and spirit. Health is the concept of being and looking clean, being well rested, feeling good, and performing one's role well. Hispanics want to be pampered when they are ill; it is a way the family can express love and concern. Many Latin Americans view thinness as a problem and plumpness as the ideal. Preventive health may be neglected because they are a "present" oriented society. Traditionally, the medical system consisted of a holistic healer who attended the social, physical and psychological needs of the person. The treatments had a religious orientation and involved rituals and artifacts; offerings of money, penance, lighting candles, wooden or metal offerings in the shape of the afflicted body part; and the laying on of hands.

<sup>&</sup>lt;sup>63</sup> Adapted from multiple sources, including: Spector, R.E..: Cultural Diversity in Health and Illness. Appleton-Century-Crofts, New York, 1979; "The Hispanic American Community," Transcultural Nursing, <a href="https://www.culturediversity.org/hisp.htm">www.culturediversity.org/hisp.htm</a>; and The Provider's Guide to Quality and Culture, <a href="https://www.erc.msh.org">www.erc.msh.org</a>.

### 3.9. END OF LIFE ISSUES

### Introduction

Care at the end of a person's life may focus on making a person comfortable, but it is also important to help family and friends cope with the illness or impending death of a loved one. Palliative care and hospice are among the choices available to families, and case managers may be able to help explain these options. Beyond medical care and support services, legal and financial questions may have to be addressed, such as advance directives, wills, or guardianship. The following is an overview of common end-of-life issues.

### 3.9.1. ADVANCE DIRECTIVES

Advance directives are documents specifying the type of treatment individuals want or do not want when they experience serious medical conditions. The documents are used when a person is unable to communicate his or her wishes. They provide written proof of the expressed wishes of the individual, rather than making the family guess what is desired. Making one's wishes known in advance helps everyone. It keeps family members from making such choices at what is likely one of the most stressful times in their lives. It also means that the physician knows whose direction is to be followed in the event the family disagrees as to what medical treatment the individual desires.

Generally, two documents are involved with advance directives:

- **1. Living will:** A legal document that outlines the medical care an individual wants or does not want if he or she becomes unable to make decisions. An example would be the use of a feeding tube.
- **2. Durable medical power of attorney:** A legal document that designates another person to act as an "agent" or a "surrogate" in making medical decisions if the individual becomes unable to do so. Note: This person would only make health care decisions. A different power of attorney is needed for financial decisions.

Advance directives can be completed by an individual. The writing does not need to be done by an attorney, but it must be done while the person is still competent. In Arizona, the forms do not have to be notarized; but if the individual ever moves to another state that requires notarization, the forms would be invalid.

### The "Orange Form": Do Not Resuscitate (DNR) Directive

A special version of the living will is the Do not Resuscitate (DNR) Directive. Formally called the *Pre-Hospital Medical Care Directive*, it is also known as the "orange form" because of the orange color of the paper it is printed on. This form says that if the heart stops beating or breathing stops, the individual does not want to receive cardiopulmonary resuscitation (CPR). This special form notifies the paramedics and emergency medical services people that this choice has been made.

### **Agency-Specific Policies and Procedures**

The policies and procedures for honoring an orange form vary from agency to agency. Some agencies have policies that mandate CPR measures whether the individual has an orange form or not. Other agencies have a procedure to follow if the individual has a valid orange form.

It is also important to remember that the orange form **only covers cardiac and respiratory arrest.** If the person has another type of medical emergency, medical care should be initiated and 911 should be called as indicated.

### **Display of the Orange Form**

Because the paramedics respond quickly to an emergency medical situation, the Pre-Hospital Medical Care Directive (orange form) must be immediately available for them to see. Therefore, it should be displayed someplace where the paramedics will be able to see it should the individual have a cardiac and/or respiratory arrest. Such places would be the refrigerator or behind the front door or living room door.

### 3.9.2. PALLIATIVE CARE

Palliative care is also called comfort care and is primarily providing relief to a terminally ill individual through symptom and pain management. The goal is to provide comfort measures that prevent and ease suffering and maintain the highest possible quality of life for as long as life remains. Palliative care aims to relieve symptoms such as pain, shortness of breath, fatigue, constipation, nausea, loss of appetite and difficulty sleeping. Palliative care programs also address mental health and spiritual needs. The focus is not on death, but on compassionate specialized care for the living that supports the whole person and those involved with them.

Palliative care may be delivered in the hospice setting, home or hospital. There are specialized care programs for the most common terminal diseases such as cancer, AIDS and Alzheimer's.

### 3.9.3. HOSPICE CARE

Hospice is a concept of compassionate support rather than a place. It is a multidisciplinary approach as an option for individuals with a terminal condition whose life expectancy is six months or less. Individuals have the right to choose to die at home or in the surroundings they choose. The focus is relief of pain and symptoms rather than curative measures, enabling individuals to live their days to the fullest, with purpose, dignity, grace, and support. Care and support is based on all aspects of life and well-being: physical, social, emotional and spiritual.

Hospice programs are generally home-based, but services can sometimes be provided at special facilities, hospitals or nursing homes. Services provided may include: nursing care, social services, physician services, clergy and other spiritual counselors, home health aid services, therapies, respite care, inpatient care, and bereavement support. Trained volunteers are available to provide socialization or respite.

Medicare, Medicaid and most private insurance plans cover hospice services. Eligibility for services requires a physician to certify a prognosis of terminal illness with a life expectancy of less than six months. An individual can go off hospice services if there is improvement or if he/she decides to seek curative measures. Individuals will remain eligible for services if it again becomes necessary with a physicians re-certification.

### 3.9.4. THE DYING PROCESS<sup>64</sup>

- Death comes in its own time and in its own way.
- Death is unique to each individual.

### One to three months prior to death...

### Withdrawal

This is the beginning of withdrawing from the outside world and focusing inward. The person's world becomes smaller, possibly involving only closest friends and immediate family. With withdrawal one will see the person possibly taking more naps, staying in bed all day, and more time sleeping becomes the norm. Verbal communication decreases and touch and wordlessness take on more meaning.

#### Food

We eat to live. When a body is preparing to die, it is perfectly natural that eating should stop. This is one of the hardest concepts for a family to accept. **It is okay not to eat.** The person dying will notice a decrease in eating. Liquids are preferred to solids. Meats are the first to go, followed by vegetables and other hard to digest foods. Cravings will come and go.

<sup>&</sup>lt;sup>64</sup> From: *Principles of Caregiving* (2008). The Arizona Direct Care Curriculum Project.

### One to two weeks prior to death...

#### Disorientation

The person is sleeping most of the time now and cannot seem to keep his or her eyes open but can be awakened from the sleep. Confusion can take place when one talks to the person, and the person may start talking about previous events and people who have already died. The focus is transition from this world to the next.

### Physical changes:

- Blood pressure often lowers; pulse beat becomes erratic, either increasing or decreasing.
- Skin color changes.
- Breathing changes; it has an erratic rhythm, either increasing or decreasing.

### One to two days, to hours prior to death...

- A burst of energy may be present.
- Breathing patterns become slower and irregular, sometimes stopping for 10 to 45 seconds.
- Congestion may be audible.
- Eyes may be open or semi-open and have a glassy haze.
- Hands and feet become purplish and parts of the body become blotchy.
- The person becomes non-responsive.

### 3.9.5. EMOTIONAL ISSUES

### **Client and Family**

Individuals are unique in their display of emotions. The fact that some people do not display what others think is "normal" does not mean that they are not grieving.

Some differences in grieving:

- Some people are quite vocal; some are quiet.
- Some are accepting; some are in denial or shock.
- Some people weep; some are very stoic (emotionless).
- Some people are angry; some may appear happy.

It is only natural that the case manager and the client build a rapport. When that person dies, the case manager may grieve as though the person was a family member. There are coping strategies and community resources available for dealing with grief.

### **Stages of Grief**

There are common phases in the grief experience, first described by Dr. Elizabeth Kübler-Ross. Individuals do not necessarily go through all these stages in order and they may repeat stages. The grief process is unique to the individual.

- 1. Shock: There is disbelief that the loss has occurred.
- **2. Denial:** Denial is a temporary buffer after unexpected news. The person refuses to accept the loss has occurred. Denial is encouraged by silence.
- **3. Anger:** Anger may be directed toward the loss, the person lost, or even a deity. Families have a hard time with anger because the anger is displaced in all directions.
- **4. Bargaining:** "Let's make a deal". The person attempts to reconcile the loss by making deals with other people, sometimes also with a deity.
- **5. Depression:** Anger is turned inward.
- **6. Guilt:** Guilt is marked by statements of "If only I had done / been . . ." It usually comes from things one cannot change.
- **7. Acceptance:** Living in the present is possible. Acceptance and hope mean that the person understands that life will never be the same but it will go on with meaning and hope.

### **Coping Strategies**

Part of healthy grieving is to allow yourself to grieve — not doing so can cause emotional and/or physical problems later on. Take care of yourself by:

- Talking Use your social support system, or talk to a clergy person or counselor.
- **Writing** Take up journaling, even writing letters to the deceased person about things you wished you had said.
- **Reminiscing** Remember the good times. Plant a garden in the person's honor, or support causes the person was involved in.
- **Getting enough sleep, exercising, and eating healthy** Keep your body healthy. Do no turn to alcohol or drugs to "numb the pain"— this usually makes the situation worse.
- **Planning ahead** Realize that anniversaries, holidays and special days will be difficult at first. Plan to spend time with a valued social support.
- Don't be reluctant to ask for help Help is out there, just ask.

Clients and Family: Case managers need to be aware of the needs of the people they are serving. If you think a client or caregivers are not grieving in a healthy way, provide them with agency or community resource options.

**Case Managers:** As previously mentioned, people grieve differently; so allow yourself to grieve in your own way. You may want to talk to a valued social support, perhaps a colleague or supervisor. You may need to have some relaxation time. Try to be good to yourself and seek out the help that you need.

### 3.9.6. CULTURAL AND RELIGIOUS ISSUES

Cultural and family differences will influence the death and dying process. Case managers need to be aware of the various beliefs and practices of the people for whom they are providing services. However, as you can see below, the cultural differences are so varied that it is difficult to become culturally competent in all areas.

Some religions or cultures

- Discourage or forbid embalming and autopsy.
- Will not allow non-family to touch the body.
- Do not want the body to be touched shortly after death.
- Cover the mirrors in the home after a family member dies.
- Remove water from the room after family member dies.

### 3.10. SAFETY AND EMERGENCY PREPAREDNESS

### 3.10.1. FALL PREVENTION, HOME SAFETY ASSESSMENT AND HOME MODIFICATION

Worried about the life-changing effects of a citizen's collapse, federal, state, and local governments and health-care agencies across the nation are campaigning to prevent falls that tax the medical system and often force independent seniors into nursing homes.

Among older adults, falls are the leading cause of injury deaths; they are also the most common cause of nonfatal injuries and hospital admissions for trauma. The Centers for Disease Control and Prevention (CDC) report that in 2000, the total direct cost of all fall injuries for people 65 and older exceeded \$19 billion, a number that may reach \$54.9 billion by 2020 (adjusted to 2007 dollars).

More troubling is that Arizona ranks sixth in the nation per capita for fatal falls among older adults. Scottsdale has the nation's highest rate of senior deaths from falling.<sup>66</sup> It is conservatively estimated that over 65% of elders who have a fall resulting in a hip fracture will not return to independent living.

The percentages of men and women who reported falling during the preceding three months of the CDC study are similar, but women reported more fall-related injuries than men did. American Indians/Alaska Natives reported the greatest percentage of falls and Hispanics reported the greatest percentage of falls with injuries. Percentage of persons reporting falls increased with age, but the percentage of persons reporting fall-related injuries was about the same in each age group. Falls and fall-related injuries deeply affect older adults' quality of life and threaten their feelings of self-confidence – to say nothing of the preventable burden on the US health care system. Effective interventions that focus on muscle strengthening exercise and balance; medication management; vision correction; home safety assessments and modifications, can prevent falls and fall-related injuries. The care manager is an important partner in these interventions.

The Arizona Department of Health Services has set a goal of cutting the number of falls in the state in half for all ages by 2010. With this goal in mind, it is clear the care manager is in a prime position to assist elders, disabled individuals, and their caregivers, in fall prevention efforts. The following guidelines are only a beginning. Specific and comprehensive strategies for fall prevention and home safety assessments are included in the Appendix under Fall Prevention and Home Modification Checklists and Resources. These materials were developed by recognized experts in fall prevention (e.g., the National Center on Injury Prevention and Control, CDC, Center for Excellence in Fall Prevention) and those cited in the resource list.

The care manager must OBSERVE, OBSERVE, OBSERVE the client's environment outside and inside the home, their functional abilities, their balance and cognitive abilities and known risk factors and then also ask about their exercise and activity habits, fall history or their fear of falling. Involve the caregiver, if there is one. The care manager must then DOCUMENT, DOCUMENT, DOCUMENT, on the ASCAP Assessment Form and Home Safety Checklist. Careful documentation allows these assessments to be used to measure improvements over time.

<sup>6</sup> Carol, Sowers, "State wants to prevent falls by elderly." The Arizona Republic, Sept. 24, 2007.

<sup>&</sup>lt;sup>65</sup> Centers for Disease Control and Prevention (CDC). Falls Among Older Adults: An Overview. <a href="http://www.cdc.gov/HomeandRecreationalSafety/Falls/adultfalls.html">http://www.cdc.gov/HomeandRecreationalSafety/Falls/adultfalls.html</a>.

Characteristics of a strong assessment and in-home evaluation process include:

- Taking into account the interaction of older adults within their environment through observing their physical engagement in actual activities of daily living.
- Allowing and encouraging them, including caregivers, to talk about their experience of falls or near-falls.
- Providing suggestions as to how they can address areas of concern and involve them in setting home modification priorities.
- Assessing environments both outside as well as inside the home (e.g., sidewalks, driveways, entrances, hallways, lighting, kitchens, bedrooms, bathrooms, etc.)
- Using a home assessment screening or checklist tool that is comprehensive, has been tested
  for reliability and validity, including clear guidelines on how to use it that have specific definitions
  of environmental features, is helpful in the process. (See the Appendix for an example).

To become more client-centered, the care manager can:

- Have a conversation with the older or disabled adult participant, and/or their caregiver if one is involved, to find out his or her home safety priorities.
- Ask participants about the circumstances surrounding recent falls. What he or she was doing at the time of the fall? How was help accessed? How long did it take to get help? Did an injury result? Was medical attention sought?
- Consider the individual's medical history and carefully assess fall risk factors associated with chronic illnesses (e.g., Parkinson's disease, stroke, multiple sclerosis, rheumatoid arthritis).
- Find out what medications participants are taking and for what purpose. Do any of these medications cause dizziness or fainting?
- Ask questions about vision such as: Do you wear glasses? How old is your prescription? Any recent changes in vision? Date of most recent test?
- Ask questions about foot care and the participant's experiences outside the home, if the client is able to leave the home.
- Look at high-risk areas in the home like kitchens, walkways and the bathroom in particular: is standard bathroom equipment in evidence - a handheld shower; grab bars; transfer bench or tub/shower chair; raised toilet seat with sturdy toilet safety frame, non-slip mats on floor and in tub, night light? Such items are often called durable medical equipment (DME).
- Does participant have a cane, walker, or wheelchair? Have they received professional instruction in how to use equipment properly? Has their house been assessed by an OT or PT?
- Refer individuals or caregivers back to primary healthcare providers for in-depth medical assessments if needed to manage chronic medical conditions.
- Ask the older adult, disabled participant and/or their caregiver, about friends, family, and service
  providers that they trusts. Involve those individuals in home safety initiatives and create
  opportunities for those supportive individuals to explain why they think specific home safety
  activities will be helpful to the participant.
- Involve the participant and/or caregiver in assisting you to complete their home safety assessment and checklist.
- Involve healthcare providers who are experienced in teaching older adults how to develop and use problem solving skills relevant to home safety and to use adaptive equipment/mobility aids.
- Develop realistic home safety goals that lead to successful outcomes. Participants will be more highly motivated to continue with home safety efforts if they experience success.

Provide regular, specific feedback to participants and/or caregivers to help them recognize that progress in home safety has been made. In addition to fewer falls, many other benefits of enhanced home safety can be recognized:

- o increased enjoyment of activities in the home,
- o increased activity levels,
- o higher levels of independence with daily activities,
- reduced fear of falling.
- A simple question during telephone follow-up can be asked, such as "Mrs. Smith, I know you loved that fluffy pink throw rug that you donated to Goodwill last month. Did you replace it? You did? Does the new one have a rubber backing? It does? Well good for you, I'm so glad to hear it, and I know your doctor will be too!"

Evaluation of fall prevention and home modifications program outcomes are important but may be difficult to quantify. Often the evaluation is limited to a description of whether or not client-specific short-term and long-term goals were met. The most common measures can include self-reported client satisfaction with improvements in activity levels, absence of falls, maintenance of changes made to the home environment and satisfaction with the ability to obtain or use assistive devices. However, it is important to keep records of what worked and what did not work in order to build program priorities. Strong case histories can be instrumental in obtaining increased resources for program improvement and expansion, as can reliable data. Additional resources for home safety and home modification interventions are not possible without reliable outcome information.

Ultimately, the best measure of effective care manager fall prevention and home modification assessment and intervention activities will be the increased safety, independence and quality of life improvements on the part of elderly and disabled program participants, and their caregivers.

Please see the Appendix under Fall Prevention and Home Safety & Modification Checklist, Assistive Devices and Fall Prevention Resources for additional information and forms.

### 3.10.2. EMERGENCY PREPAREDNESS

Case managers should have a general discussion with clients and/or their caregivers about their plans and preparations in case an emergency or disaster strikes. Questions to prompt general thinking and planning can be asked, such as:

- Do you have 911 posted by your telephone?
- Do you have the names and numbers of emergency contacts?
- Does a trusted relative or friend have a key to your house?
- Do you have a living will?
- Do you have a medical power of attorney?
- What would you do if the resources you used on a daily basis were limited or unavailable, such as medical facilities, pharmacies, or in-home services?
- Do you have a plan for taking care of your pets?
- Where would you go if you had to evacuate?
- Do you have mobility limitations?
- Would you need assistance to evacuate? (This is documented on the ASCAP)
- Do you have an Emergency Supply Kit? Does it include a 3-5 day supply of necessary medications?
- Do you have a supply of shelf stable meals? These meals do not require refrigeration and can be consumed at room temperature.
- How would you get water if the supply was shut off?

These examples of general questions to ask at the initial in-home assessment visit would set the stage for presenting the new client or caregiver with a checklist or a form for an emergency plan. **Several checklists are included in the Appendix.** It should be documented in the client's case file that a checklist was given to the client, but it is not the case manager's responsibility to complete a checklist for each client. A review of the client's completed checklist could then be done at the 90-day follow-up and at semi-annual re-authorization visits; these dates would then be documented in the client case file.

Those clients who need assistance in developing an emergency plan or those who need help in obtaining needed items to complete their Emergency Supplies Kit should be identified. Battery operated radios and first aid kits are the most expensive items on this list, which might be a barrier to low-income individuals. It is possible to identify community partners who may be able to help provide these items. Partners such as service clubs, churches, first responder organizations and Area Agencies on Aging may be able to assist.

By having this conversation with clients and by providing them with the resources needed to help themselves, the case manager becomes an integral part of their community's emergency preparedness team. The case manager should stress, however, that assistance in an emergency cannot be guaranteed and that clients and caregivers must prepare themselves to be self sufficient for a number of days in case of a large scale community emergency.

### Resource Links:

#### Arizona:

Arizona Department of Economic Security, Division of Aging and adult Services, (602) 542-4446, http://www.azdes.gov/daas

Arizona Department of Health Services, (800) 314-9243, <a href="www.azdhs.gov">www.azdhs.gov</a> Arizona Department of Emergency and Military Affairs, (800) 411-2336, <a href="www.asdema.gov">www.asdema.gov</a>

### **Nationally:**

Centers for Disease Control and Prevention, (800) 232-4636, (888) 232-6348 (TTY), <a href="www.cdc.gov">www.cdc.gov</a> FirstGov.gov, The U.S. Government's Official Website, (800) 333-4636, <a href="www.firstgov.gov">www.firstgov.gov</a> Department of Homeland Security, (800) 327-3239, <a href="www.ready.gov">www.ready.gov</a> and <a href="www.dhs.gov">www.dhs.gov</a>

### 3.10.3. SAFETY FOR CASE MANAGERS AND SERVICE STAFF

As a case manager, you may encounter people who are emotionally disturbed, severely impaired by alcohol or drugs, or involved in heated arguments with other family members that have the potential to turn violent. It is important for you to know how to protect yourself as well as what to do to prevent or diffuse a hostile or dangerous situation.

First rule: Your safety and welfare are paramount!

Second rule: Always be prepared. Certain precautions should routinely be taken with every client.

### Precautions to ensure case manager safety

- Always leave a schedule and location of visits at your office.
- Notify the office of any schedule changes.
- If you go to an unfamiliar location, consider driving by before you return and park.
- Do not park directly in front of the building or in the driveway so that a client will not get upset at possibly having the driveway blocked.
- In an unfamiliar building, position yourself to have clear access to an exit.
- Do an environmental assessment, i.e. animals, unsafe steps, loose boards, etc.
- Ask who is in the home.
- Ask about animals before visiting, and take necessary precautions.
- Note the location of doors / exits.
- Keep your keys on your person.
- Do not hesitate to leave at any sign or threat of danger.

**Remember:** If anything about the situation does not feel safe to you, don't go in alone. Trust your instincts!

### Warning signs that may predict danger

### Non-verbal signs include:

- A build-up or intensification of physical activity: banging things, throwing things, kicking, agitated pacing.
- Body language: threatening gestures, increased muscle tension, clenched fists, reddened face, rapid eye movements or refusal to establish eye contact, gritting teeth.

### Verbal signs include:

 Raised voice, agitated or quickened speech, muttering, and increase in use of obscene language.

People who act out their anger and become violent often go through cycles. They may enjoy times of relative quiet before they enter periods of time in which they become increasingly anxious and agitated. Know the signs.

### Attitudes and approaches to minimize danger<sup>67</sup>

#### Attitude

- Remain calm.
- Be non-judgmental.
- Avoid threatening words or actions.
- Show concern.
- Be empathetic.
- Be aware of posture and tone of voice.

#### **Body Language**

<sup>&</sup>lt;sup>67</sup> Adapted from multiple sources, including Children's Services Practice Notes, <a href="http://www.practicenotes.org/vol3">http://www.practicenotes.org/vol3</a> no2/predicting violence.htm.

- Avoid extensive eye contact and physical closeness. Don't touch an angry person.
- Appear non-confrontational. Position yourself slightly to the side of the person. This is less
  threatening and offers people a perceived route of escape. Standing face to face can be
  perceived as challenging and confrontational.
- Convey a neutral or non-threatening impression, which is very important when interacting
  with people in highly emotional states. Avoid putting your hands on your hips, and don't.

### Speech

- Avoid sounding sarcastic, frightened, insulting, or angry.
- Keep tone of voice smooth and supportive; speak only as loudly as needed to be heard.
- Speak in a normal rhythm--too fast or too slowly increases irritability.
- Use simple, direct, clear language.
- Speak in short sentences.

#### **How to Protect Yourself**

- Document when problems arise.
- Act in good faith.
- Follow the rules and policies.
- Consult supervisor if a problem arises.

### 4. APPENDIX

### 4.1. SCOPE OF WORK: CASE MANAGEMENT

#### 15.0 CASE MANAGEMENT

#### 15.1 Purpose Statement

15.1.1 The service identifies, facilitates, and coordinates formal and informal services in order to assist clients to maintain independence and avoid institutional placement, while complementing caregiver support.

### 15.2 Service Description

- 15.2.1 Taxonomy Definition A service or process that establishes a relationship with an individual or family in order to enhance their functioning and/or integration into the community. Appropriate services and/or benefits are identified, planned, obtained, provided, recorded, monitored, modified when necessary and/or terminate. This may include: assessment to determine their needs and eligibility when applying for/receiving services, assistance in obtaining entitlements, communication and coordination of care as well as follow-up of crisis contacts or missed appointments.
- 15.2.2 Case management is a service or process that establishes a relationship through a strength-based collaboration with an individual, family and/or caregiver in order to assist individuals in organizing and managing their care by coordinating and facilitating access to a variety of services in a timely manner.
- 15.2.3 Appropriate services and resources, including home and community-based services (HCBS), are identified, planned, obtained, provided, recorded, monitored, modified when necessary and/or terminated.
- 15.2.4 Case management consists of intake and screening, assessment, service planning and implementation, follow-up and monitoring, and reassessment and termination of services.
- 15.2.5 Screening and/or intake may be provided before a referral to case management is made.
- 15.2.6 Specifically related to the Family Caregiver Support Program, case management for a caregiver is considered a counseling service focused on the needs of the caregiver and doesn't include client (carerecipient) assessment or authorization of client-supported services.
- 15.2.7 Eligibility Requirements The Contractor shall provide services to individuals that meet the eligibility requirements described in chapter 3000, as may be amended.

#### 15.3 Service Requirements – The Contractor shall:

#### 15.3.1 Provide Intake

- 1. Provide intake of the client.
- Identify and record name and contact information of the individual or caregiver who is seeking assistance.
- 3. Identify and record information regarding self-assessment of health and of Activities of Daily Living (ADLs) and Instrumental ADLs (IADLs), assets and resources, and formal and informal support systems.
- 4. Identify and record the individual's wants, problems, strengths and needs, or caregiver's level of stress.
- 5. Provide the individual or caregiver with information about available services, eligibility, and conditions of acceptance for services.
- 6. Inform the individual or caregiver of his/her rights and responsibilities in relation to services.
- Arrange for or facilitate access to one-time-only or emergency services needed by the individual or caregiver. Document the name of the individual or caregiver and the type of service for which arrangements were made.
- 8. Determine if the individual or caregiver is appropriate for case management or for an assessment.

#### 15.3.2 Provide Assessment

- 1. Provide an in-home visit by a case manager to conduct an in-depth assessment using an ADES approved tool (see DAAS Policy and Procedure Manual chapter 3000, as may be amended).
- 2. Assess the client's strengths based on daily living situation, health, finance/insurance, social supports, leisure/recreational activities, spirituality/religion and develop a service plan in collaboration with the individual or caregiver and other appropriate persons.
- 3. Establish and record the individual's or caregiver's goals.
- 4. Client-supported caregiver services require additional assessment using an ADES approved tool. (See DAAS Policy and Procedure Manual, as may be amended).
- 5. Determine if the individual or caregiver is eligible to receive services.

#### 15.3.3 Develop a Service Plan

- 1. Identify and record what services have been chosen to be provided to the individual or caregiver.
- 2. Identify and record how services will be provided.
- 3. Identify and record who will provide the service.
- 4. Identify and record, with input from the individual or caregiver, when the plan will begin, when it is to end, when specified milestones are to be accomplished and when progress is to be assessed.
- 5. Identify and record the criteria for measuring the results to be achieved by the plan.
- 6. Identify and record the process to be utilized for renegotiating the service plan.

#### 15.3.4 Provide Service Plan Implementation

- 1. Authorize and record the covered services to be provided to the individual or caregiver.
- 2. Record referrals made for non-covered services (services other than those authorized).
- 3. Give each individual seeking services a list of agencies that provide similar services.
- 4. Coordinate and facilitate the access to and the delivery of services to the individual or caregiver and record this information.
- 5. Assist the individual or caregiver in obtaining needed services and resources through education and advocacy.
- 6. Provide direct intervention to assist with the individual or caregiver's overall goals.

#### 15.3.5 Provide Service Plan Monitoring

- 1. Determine and record the type and quantity of services the individual or caregiver received.
- 2. Identify and record the individual or caregiver's progress toward established goals.
- 3. Identify and record the quality and appropriateness of the services provided.
- 4. Identify, record and reassess the service goals and resolve any problems related to the service assist the individual or caregiver with appeals, hearings and/or grievances.
- 5. Determine and record the individual or caregiver's continued eligibility and need for services.
- 6. Conduct a review of the entire service plan at least every six months.
- 7. Conduct a reassessment of the individual's needs and preferences annually or if changes have occurred since the last review.
- 8. Follow up to determine whether changes were implemented.

#### 15.3.6 Provide Service Plan Closure

- 1. Identify, assess and record the individual or caregiver's progress toward his/her goals.
- 2. Identify and record the individual or caregiver's status at the close of the service plan.
- 3. Identify and record the reasons for closure of the plan.

#### 15.4 Staffing Requirements – The Contractor shall:

- 15.4.1 Ensure that case managers have at a minimum a Bachelor's degree in social work, sociology, psychology, counseling, nursing, or other closely related fields, or have two years' experience in social or health services.
- 15.4.2 Ensure that the Case Management Supervisor has at least a Master's degree or at least four years experience in social or health services.
- 15.4.3 Ensure that case managers have a thorough knowledge of the services provided by their respective programs and an understanding of procedures for integrating services.
- 15.4.4 Ensure that case managers have the knowledge, skills, and experience necessary to assess the client's strengths and need for services and perform the core functions of case management.
- 15.4.5 Ensure that case managers ensure that appropriate assistance is given to each client, family member, caregiver, or client's legal representative, by providing accurate and complete information about available services allowing the individual self-directed care.
- 15.4.6 Ensure that case managers display effective communication skills and be able to work as part of a team of service providers on behalf of the client.
- 15.4.7 Ensure that case managers assume responsibility for their own professional growth and continuing education to enhance their case management skills, and keep up with the many changes of available resources in the health and social service fields.
- 15.4.8 Ensure that case managers do not engage in any personal relationships with the client, caregiver, or family members that may lead to any personal or professional gain or impair professional judgment.

- 15.4.9 Ensure that staff providing intake have the knowledge, skills, and experience necessary to ensure that clients are referred to case management as appropriate.
- 15.4.10 Ensure that a newly hired employee providing case management services shall submit three references from persons other than family members in order for the Contractor to verify the employee's previous employment record. All references, whether verbal or written, shall be contacted and results documented in the personnel record.

#### 15.5 Performance Measures

- 15.5.1 Percentage of clients 60+ years of age with severe disabilities (3+ ADL limitations) who receive Case Management services.
- 15.5.2 Percentage of clients 60+ years of age living below the poverty level who receive Case Management services.

### 15.6 Reporting Unit

15.6.1 One case management unit of service equals 60 minutes of service time.

Client:	Ca	se Manager:		Date:	
Client Strengths:					
Client Support Syster					
Plan begin date:	Plan end date:	Plan review dates	(q90 days):		
PRESENTING ISSUE	GOAL	OBJECTIVE	TARGET DATE	DATE ACCOMPLISHED	OUTCOME
My long term goal:					
Date:					
Case Management:					
<ul> <li>Client is unaware of community resources and how to access them.</li> <li>Caregiver needs additional support.</li> <li>Supportive mentoring and guidance required.</li> </ul>	<ul> <li>Maintain the client in the least restrictive environment.</li> <li>Coordination of services as outlined by the client/family.</li> <li>Client advocacy.</li> <li>Maintain communications with participating professionals, family, etc.</li> <li>Provide support to caregiver to assist care recipient to remain at home.</li> </ul>	Client will receive support /advocacy for Case Management in linking services.			
Home Delivered Meals:	nome.				
<ul> <li>Client is at nutritional risk due to poor diet.</li> <li>Client's frailty makes it difficult to stand or prepare meals.</li> <li>Provide support for caregiver.</li> </ul>	<ul> <li>To improve client's nutrition by the provision of HDMs.</li> <li>To supplement client's independence in meal preparation.</li> <li>To supplement care for the caregiver.</li> </ul>	<ul> <li>Client will receive         HDMs on a regular         schedule.</li> <li>Family members         will assist with meal         preparation on         weekends and         evenings.</li> </ul>			
Housekeeping:		, and the second			
<ul> <li>Client has an acute condition and is unable to clean the house.</li> <li>Client has a chronic condition and is unable to clean the house.</li> <li>Client is unable to bend, stoop or stretch and is unable to clean the house.</li> <li>Caregiver is unable to provide housekeeping tasks due to frailty/stress.</li> </ul>	<ul> <li>Maintain a safe and sanitary living environment.</li> <li>To supplement client's independence in housekeeping.</li> </ul>	□ Client will receive housekeeping services in the following areas: □ General □ Housekeeping □ Laundry □ Shopping □ Meal □ Preparation □ SPP Check □ Client/family member will complete the following tasks: □ General □ Housekeeping □ Laundry □ Shopping □ Meal □ preparation			

	PRESENTING ISSUE	GOAL	OBJECTIVE	TARGET DATE	DATE ACCOMPLISHED	OUTCOME
Per	sonal Care:			5,2	, io com Lioned	
	Client is frail and unable to safely attend to personal care needs.  Caregiver needs assistance in providing personal care needs due to personal frailty.	<ul> <li>To assure the client's hygiene and personal care needs are met.</li> <li>To assist the caregiver in meeting client's hygiene needs.</li> </ul>	Client will receive assistance in personal care in the following areas:  Bathing Dressing Grooming			
Have	va Haalih Aida		The client/family member will complete the following tasks:  □ Bathing □ Dressing □ Grooming			
Hoi	ne Health Aide:					
	Client is frail and unable to safely perform ADL to continue to live independently. Caregiver needs assistance in providing health maintenance and monitoring.	<ul> <li>To provide health maintenance.</li> <li>To provide on-going monitoring of a health condition.</li> <li>To provide transfers.</li> <li>To teach and encourage family members to provide home health tasks.</li> </ul>	Client will receive assistance of a HHA in the following areas:  Medication Monitoring Vitals Transfers Bathing  The client/family member will			
Nur	sing:		complete the following tasks:			
		" " "				
	Client's memory loss interferes with the ability to take medication accurately. Client's medical condition requires monitoring. Caregiver needs assistance in medication management.	<ul> <li>To monitor client's overall health condition on a regular basis.</li> <li>To provide medication set- up and ensure compliance.</li> <li>To teach the caregiver about medication management.</li> </ul>	Nurse will set up medications:    weekly     bi-weekly     monthly     Nurse will monitor client's health status:   weekly     bi-weekly     monthly     Nurse will teach family member			
			medication management and monitor this activity:  weekly bi-weekly monthly			

PRESENTING ISSUE		GOAL	OBJECTIVE	TARGET DATE	DATE ACCOMPLISHED	OUTCOME
Respite Service:				27112	7.000.m 2.0.125	
<ul> <li>Caregiver has need for temporary relief due to personal health proble</li> <li>Caregiver needs temporary relief from caregiving tasks.</li> </ul>		☐ To eliminate overall stress level for the caregiver.	Client will receive:  In-home Respite Group Respite Facility Respite			
Adult Day Health Care:						
□ Client is at risk for soci isolation or depression □ Caregiver has need of relief.		□ To prevent depression due to social isolation. □ To improve client's socialization skills. □ Provision of activities in a group setting outside of the living environment. □ To provide caregiver with temporary relief of their caregiving responsibilities.	Client will attend ADHC on a regular basis.			
Mental Health:						
<ul> <li>Depression related to physical disability.</li> <li>Depression related to limited income.</li> <li>Depression related to personal issues.</li> </ul>		Alleviate depression.	Refer client to Counseling services.			
Transportation:						
Client does not drive. Client is unable to accupublic or private transportation services	ess i.	□ To assist client with skills and information needed to access transportation services. □ To improve client socialization and decrease isolation. □ To increase client's independence. □ To provide transportation to appointments.	Client will receive transportation by accessing appropriate resources.			
Housing:		☐ To decrease isolation.	To access			
		<ul> <li>To decrease financial burden.</li> <li>To obtain a safe and secure living environment.</li> <li>To offer improved access to public transportation.</li> </ul>	appropriate housing to best meet client's needs.			
Shopper:						
<ul> <li>Client is unable to walk stand long enough to shop for groceries.</li> </ul>	cor	☐ To obtain food, medication, household supplies, etc. for client.	To provide client with the necessary food, medications, household supplies, etc. as needed.			

PRESENTING ISSUE	GOAL	OBJECTIVE	TARGET DATE	DATE ACCOMPLISHED	OUTCOME
Home Adaptation:					
<ul> <li>Client has environmental needs which require adaptation.</li> <li>Client has environmental needs which require repair.</li> </ul>	<ul> <li>To provide a safe living environment and improve independent functioning in the home.</li> <li>To respond to environmental needs impacting client's health.</li> <li>To increase sense of independence.</li> </ul>	☐ Client will receive maintenance assistance.			
Reassurance Emergency Alert System:					
Client has a medical condition which prevents them from accessing emergency assistance.	☐ To ensure that the client has access to an emergency response system.	☐ Client will have an Emergency Alert System installed in their home.			
Sheltered Employment:	□ To ensure that the client	□ Client will attend			
<ul> <li>Client is unable to work independently due to a medical or psychological condition.</li> </ul>	is provided the opportunity for vocational activity in the least restrictive environment.  To improve client's functional capacity. To improve client's socialization and build confidence and self esteem.	Sheltered Employment where support and supervision will be received.			
Other:					
Other:					
Other:					

# SERVICES PROVIDED BY A COMMUNITY SERVICES SYSTEM CONTRACTED PROVIDER UNLESS OTHERWISE STATED

Client's signature	Date
Responsible Party's signature	Date
Case Manager's signature	Date

### 4.3. FALL PREVENTION AND HOME MODIFICATION – ADDITIONAL RESOURCES 68

### FALL PREVENTION AND PERSONAL SAFETY CHECKLIST

Falls are not just the result of getting older. They don't "just happen." Usually there is a "risk factor" involved. A risk factor is something that increases your chance of falling, such as muscle weakness, balance problems, vision problems, medications, blood pressure changes, foot problems, and unsafe surroundings. Risk factors can also include pets (cats, dogs, bunnies, etc). These falls can be prevented. By changing your risk factors, you can lower your chance of becoming an unhappy statistic! This tool can assist older, disabled individuals and caregivers assess possible hazards and functional performance within the home. It can allow them to initiate problem-solving strategies, make educated decisions regarding adaptive equipment, and most importantly, prevent falls and enhance independence.

Have you had any recent falls (within the past 6 more)	ntns)?
• What were the circumstances surrounding this fall?	
What were you doing at the time of the fall?	
How did you get help?	
How long did it take for help to arrive?	
Did an injury result?	
Did you obtain medical attention?	
What changes have you made as a result?	
<ul> <li>What additional changes would you like to make?</li> </ul>	
KERCISE:  egin a regular exercise program, if you do not do so alrea  reduce your chance of falling! It makes you strong	
egin a regular exercise program, if you do not do so alreated reduce your chance of falling! It makes you strong proves balance and coordination (like Tai Chi) and flexible.  Lack of exercise leads to weakness and increases you	er and helps you feel better. Exercise lity (like Yoga) are the most helpful.
egin a regular exercise program, if you do not do so alreated reduce your chance of falling! It makes you strong proves balance and coordination (like Tai Chi) and flexible	er and helps you feel better. Exercise lity (like Yoga) are the most helpful.
egin a regular exercise program, if you do not do so alreate reduce your chance of falling! It makes you strong proves balance and coordination (like Tai Chi) and flexible.  Lack of exercise leads to weakness and increases you day?  Many older people enjoy walking, swimming and game of the weight-bearing activities such as walking and coordination. Have you been screened become one people who exercise regularly experience better here.	er and helps you feel better. Exercise lity (like Yoga) are the most helpful.  Four chance of falling. Do you exercise extended by the loss of the loss of the loss of limbing stairs may even slow the loss of the loss of little and improved mood. How would you
egin a regular exercise program, if you do not do so alreat reduce your chance of falling! It makes you strong proves balance and coordination (like Tai Chi) and flexible.  Lack of exercise leads to weakness and increases you day?  Many older people enjoy walking, swimming and game.  Mild weight-bearing activities such as walking and coordination. Have you been screened.	er and helps you feel better. Exercise lity (like Yoga) are the most helpful.  Four chance of falling. Do you exercise extractions. What do you like to do?  Imbing stairs may even slow the loss of d for this?  alth and improved mood. How would you nters, parks, and recreation facilities. Wo

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<sup>&</sup>lt;sup>68</sup> Provided by the Pima Council on Aging.

### **MEDICATIONS AND MEDICAL CONDITIONS:**

As we get older the way some medicines, or combinations of medicines, work in the body can cause side effects or make us drowsy or light-headed, which can lead to a fall. People who take a least four prescription drugs have a greater risk of falling.

•	herbal supplements?
•	Have you had your doctor or pharmacist look at ALL your medications, including those bought over-the-counter without a prescription?
•	Do you have all your prescriptions filled at the same pharmacy?
•	Have you discussed possible side effects with your pharmacist or doctor?
•	If you get hot, especially when taking some meds, you might get dizzy and faint. Are you careful about drinking lots of water, especially in the summer?
•	Do you have any chronic illnesses like Parkinson's disease, stroke, multiple sclerosis, rheumatoid arthritis?
•	Which do you take:
	o Alcohol
	<ul> <li>Anticonvulsants</li> </ul>
	<ul> <li>Antidepressants</li> </ul>
	<ul> <li>Antihistamines</li> </ul>
	<ul> <li>Anti-inflammatories</li> </ul>
	<ul> <li>Antipsychotics</li> </ul>
	<ul> <li>Blood pressure meds</li> </ul>
	o Laxatives
	o Narcotics
	o Parkinson's Drugs
	Tranquilizers/Sedatives/Hypnotics
	Water pills
	o Other:
•	Do any of the medications you take cause dizziness or fainting?
•	If you take high blood pressure medicine, are you careful not to get up too quickly after eating, lying down, or resting?
•	Even a small amount of alcohol can affect your balance and reflexes, or interact with your medications.
	Do you limit your alcohol intake?
	When do you have alcohol?
	How much do you usually have?

V1210	N AND REARING:
•	Do you wear glasses?
•	Do you keep them clean?
•	Are you extra cautious when you get new glasses?
•	How old is your prescription, when did you last have an eye exam?
•	Have you had any recent changes in vision?
•	Do you have:
	o Cataracts
	<ul> <li>Macular degeneration</li> </ul>
	o Glaucoma
•	Do you wear sunglasses on bright days?
•	Do you take them off when entering a building?
•	Do you have trouble hearing clearly?
•	Have you had your hearing tested?
•	Do you wear a hearing aid?
•	Is it in good working order?
•	Does it fit well?
FOOT	CARE:
•	Do you avoid shoes with slippery soles or high heels?
•	Do you avoid floppy, backless slippers?
•	Are your shoes easy to walk in with non-skid soles that give good support?
•	Do your shoes surround your foot?
•	Do you need a cane or walker to help maintain balance?
OUTS	IDE THE HOME:
•	Are you aware of your surroundings?
•	Do you use a cane, walking stick or walker to help maintain balance?
•	Do you use a seated walker, scooter or wheelchair?
•	Do you need assistance in transferring?
•	Do you avoid wet, icy or slippery surfaces?
•	Do you use a small cart to avoid overloading yourself with packages?
•	Are you cautious when getting on or off a bus or in and out of a car?
•	Do you take your time and look carefully when crossing intersections?
•	Do you remain "pet aware" - if walking your dog?
•	Do you carry a whistle or cell phone to summon assistance if needed?
	Has your doctor suggested you use a walking stick, cane or walker?

#### WHAT TO DO IF YOU FALL:

Whether you are out and about or at home, a sudden fall can be startling, upsetting and perhaps painful. If you do fall, stay as calm as possible!

- Take several deep breaths and try to relax.
- Remain still on the ground or the floor for a few moments.
- Try to determine if you are injured.
- If you are injured, have hit your head, experience confusion, or severe pain in your groin, call 911 immediately.
- Even if you are not injured, write down when, where and how you fell.
- Discuss your fall with your doctor to assess if a medical condition needs to be addressed.
- Knowing the cause can help you prevent future falls.
- A physical therapist can help with gait, balance, strength training and walking aids.
- An occupational therapist can assess changes in your home and activities to lower your risk.
- Fear of falling may prevent you from doing the very things that can prevent future falls!
- Stay active and keep a positive attitude; a class such as "A Matter of Balance" can help you
  overcome your fears.

## **HOME SAFETY & MODIFICATION CHECKLIST<sup>69</sup>**

### (Page 1)

Ask yourself the following questions, or better yet, have a trusted friend or relative go over them with you as you inspect your home. Mark all "NO" answers. These are areas that need improvement. If you cannot make improvements in these areas, or need help to do so, report them to your care manager at his/her next visit. Your care manager may have some suggestions, information, or services to assist:

### **ENTRANCE:**

- Is the sidewalk or driveway free of tripping or sliding hazards?
- Are sidewalk, driveway or steps slippery when wet?
- Are cracks, potholes, soft dirt, sand, rocks, gravel, and tree roots absent?
- Are thresholds clearly marked and free of obstructions?
- Are steps steady and in good repair?
- Are top and bottom steps marked with reflecting paint or tape?
- Is a secure railing present or handrails on both sides that are easy to grip?
- Is there grasping space for both knuckles and fingers on railings?
- Are the stair treads deep enough for your whole foot?
- Are any low-rise steps, porches or landings in good repair?
- Is a ramp feasible in any area if one needs to be installed?
- If there is a ramp, does it meet ADA specifications? (12" L for each 1" H X 36" W)
- Can you enter the house or apartment safely?
- Is it well lighted?
- Can the light be turned on without having to walk through dark areas?
- Is there an automatic motion detector light at night?
- Is the entry free of shrubbery or bushes that hide the door?
- Is the doorway wide enough for easy and unobstructed entry?
- Can you view visitors from inside the house?
- Is the lock and deadbolt in working order?
- Is there a doorbell or knocker?
- Are all locks throughout the house keyed the same?
- Are the doorknobs lever-type handles?
- Is the mailbox easily accessible?
- Is parking space available, convenient to entranceway?
- If there is a garage, does it have an automatic opener?
- Are any hoses, tools or debris properly stored away?
- Is a spare key hidden outside or with a trustworthy neighbor?

- Is there a dog or other pet?
- Do you need a wheelchair and/or a wheelchair ramp?
- Do you need help to make adaptations or modifications?

NOTES:	List changes	or improve	ments to I	be made;	timeline fo	or completion;	who will	be respons	sible
who will f	ollow-up.								

<sup>&</sup>lt;sup>69</sup> Prepared by a workgroup led by the Pima Council on Aging, to be used in combination with assessment instruments such as the ASCAP

### (Page 2)

#### LIVING AREAS:

- Are floors non-glare, without checkered or geometric patterns?
- Is non-slip floor wax used?
- Are all pathways free of electric cords?
- Are interior thresholds marked with reflecting tape, leveled or removed?
- Are interior steps or surface drops absent?
- Are all carpets, tiles and runners secured?
- Are floors kept free of scatter or throw rugs?
- Are floors and stairways free of clutter, papers, shoes, clothes?
- Do interior doors have lever-style handles?
- Are windows and doors easy to open and close?
- Can windows be locked?
- Are screens in good repair? (West Nile)
- Are doorways wide enough for a walker/wheelchair (32"-36")
- Is there space to maneuver while opening and closing doors?
- Are your hips at the same level as your knees when seated on:
  - Sofa or couch
  - Dining room chair
  - Favorite easy chair
- Is furniture sturdy and heavy?
- Are couches and chairs at proper height to get into and out of easily?
- Do couches and chairs have armrests?
- Are furniture, (especially low coffee tables) and other objects arranged so they do not interfere with walking?
- Is there a minimum of 32" -36" of space between furniture?
- Are furniture and commonly used items kept in the same place?
- Are extra clutter, furniture and knickknacks cleared away?
- Are tall bookcases or cabinets secured to the wall?
- Are guns locked up or removed?
- Do you keep a "go-pack" with 3-5 days of emergency supplies available?

- Is a lift-chair needed?
- Do heaters or radiators need guards?
- Is there lead-based paint on any walls, doors, window sills? (painted prior to 1972)
- Do you need to apply for low-income utility programs?
- Do you need help to re-arrange furniture?
- Do you need help to sort and discard old or broken things?

NOTES:	List changes	or improv	vements t	to be	made;	timeline	for	completion;	who	will be	respons	sible;
who will f	ollow-up.											

### (Page 3)

#### LIGHTING/ELECTRICAL/ALARMS:

- Do you always turn on the light when entering a dark room, even if it is familiar?
- Are 100-watt, low-energy florescent bulbs used wherever possible?
- Can low wattage fixtures be replaced with 100-watt fixtures?
- Can you safely replace burned out bulbs on ceiling or porch lights by yourself?
- Do you know where breaker switches or fuses are located?
- Do you know how to turn off the electricity safely?
- Do windows have sheers to reduce glare?
- Is there a bedside lamp and flashlight, with extra batteries, handy?
- Are there night-lights throughout the home, especially in halls, baths and bedrooms?
- Are stairs lighted at top and bottom?
- Do lamps have shades to reduce glare?
- Does lighting placement avoid dark spots?
- Is lighting sufficiently bright for purpose of area?
- Are outlets and switches easy to turn on and off?
- Do you check that outlets, switches or cords are not warm to the touch?
- Can large, lighted rocker light switches be installed if needed?
- Are electric outlets 27 inches above the floor?
- Are outlets properly grounded to prevent shocks?
- Are extension cords in good condition, with no frayed areas?
- Are they put away promptly after temporary use?
- Are all cords out from underneath carpeting and furniture?
- If portable fans are used in the summer, are pathways free of cords?
- Do you have an alarm system?
- Do you have smoke detectors in hallways and kitchen?
- Do you replace batteries when needed?
- Do you have a carbon monoxide detector?
- Are phones available in low, easy to reach locations?
- Is there a cordless telephone or cell phone you can take from room to room?
- Are you careful to avoid pathways or tangling the phone cord when in use?
- Do you have an answering machine to take calls, to prevent running?
- Is the telephone equipped for hearing enhancement if necessary?
- Are emergency numbers in large print posted next to all phones?
- Can you hear the phone and doorbell from all areas of the house?
- Do you have an emergency evacuation plan?

- Do you need a phone or the Telephone Assistance Payment Program (TAPP)?
- Is a volunteer telephone reassurance program needed?
- Is a personal electronic emergency alert system needed?
- Do you need electric outlet plugs in case small children visit?

NOTES:	List chang	ges or	improvements	to be	e made;	timeline	for o	completion;	who	will b	e re	sponsib	le
who will f	ollow-up												

### (Page 4)

#### KITCHEN:

- Are the appliances in working order?
- Can you manipulate the sink faucets?
- Can you easily clean the sink and wash dishes?
- Is the hot water heater regulated to prevent scalding or burning?
- Do you know how to turn off the water and gas/propane?
- Are spills wiped up immediately?
- Is the floor non-slippery and easy to clean?
- Can you open and close the refrigerator and freezer?
- Is there a counter or sturdy table next to the refrigerator or freezer?
- Do you date food in the refrigerator, especially leftovers?
- Can you open and close high and low cabinets?
- Are cabinet knobs easy to use?
- Is adequate workspace available?
- Is counter height and depth good for you?
- Can you sit while working?
- Can you reach the dishes, pots, silverware and food supply?
- · Are heavy objects stored in lower cabinets?
- Do you store frequently used items at convenient heights (waist level) to avoid reaching, stooping and lifting?
- Can you reach the stove controls?
- Are stove controls easy to use?
- Can you manage the over door?
- Are flammables kept away from the stove area?
- Are cleaning supplies and pesticides stored away from foodstuffs?
- Do you avoid reaching over burners to get spices or to open cabinets?
- Can you safely transport food to eating area?
- Do you use a push-cart to move heavy or hot items to the table?
- Are sharp objects stored away safely?
- Do you only use a stepstool when another person is present?
- Do you only use a sturdy stepstool, with a handle, that can be grasped while on the top step?
- Do you have a "reach stick" to grasp objects from the floor or top shelves?
- Do you keep shelf-staple meals and water on hand in case of emergency?

- Do you need child-safety gates or safety latches on locks or cabinets in case children visit?
- Do you need help to re-arrange items in your kitchen?
- Does your kitchen need any adaptations?
- Do you need nutritional supplements?

NOTES:	List changes	or imp	rovements	to I	be	made;	timeline	for	completion; v	who	will I	be	responsi	ble;
who will fe	ollow-up.													

### (Page 5)

#### **BATHROOM:**

- Is the doorway accessible? (32" to 36")
- Can you easily manipulate the door and faucet handles?
- Are floor surfaces dry and non-slippery?
- Do floor mats have rubber, no-skid backing?
- Can you manipulate the light switches?
- Is there a night light?
- Do you take a whistle, cordless, or cell phone with you into the bathroom?
- Can you get in and out of the tub or shower with ease?
- Do you have a sturdy bath or shower seat?
- Do you have a hand-held, adjustable showerhead?
- Are there grab-bars where needed, by the shower, tub and next to the toilet?
- Are the walls of sufficient strength to support grab bars (minimum 2x4, 18" on center) or could they be reinforced?
- Does the tub or shower have a non-skid surface?
- Do you have a transfer bench to safely enter and exit the tub?
- Is the hot water set to under 120 degrees?
- Are your hips at the same level as your knees when seated on the toilet?
- Do you have a raised toilet seat?
- Do you have a toilet safety frame?
- Do you know how to turn off the water to the sink, toilet or tub if a leak should develop?
- Do you store your medicines outside of the bathroom?
- Are all medicines stored in their original containers and clearly marked?
- Is there a first floor bedroom and bath to allow living on one level if necessary?

- Do you need any of the following? Grab bars, transfer bench, handheld shower, shower chair, raised toilet seat, toilet safety frame.
- Can you obtain a prescription for these from your doctor?
- Are these covered, in whole or in part, by your medical insurance carrier?
- Do you need incontinence supplies?
- Do any adaptations need to be made?

NOTES:	List chang	ges or	improvements	to be	e made;	timeline	for (	completion;	who	will b	e i	responsible	€;
who will fe	ollow-up												

### (Page 6)

#### **BEDROOM:**

- Is the doorway accessible? (32" 36")
- Are your hips at the same level as your knees when seated on the bed?
- Can you get up and down safely from the bed?
- Do you have a firm chair with armrests in which to sit and dress?
- Do you keep bed covers, pillows, slippers, clothing or shoes from cluttering the floor?
- Is a light switch or lamp accessible from the bed?
- Is there a night light?
- Do you keep a flashlight, with extra batteries, next to your bed?
- Can you reach the phone from your bed?
- Are emergency numbers, in big print, next to the phone?
- Can you easily reach your clothes in the closet and dresser?
- Do you keep closets and drawers free of clutter?
- Does your closet have a light?
- Is there a clear path to the bathroom?
- Are any area rugs firmly secured to the floor?
- Is carpeting kept in good condition without frayed ends, puckers or tears?
- Is there a smoke alarm outside the bedroom door?
- Do you have two escape routes from your bedroom?

#### YES ANSWERS - DISCUSS WITH CAREMANAGER:

- Do you smoke in bed?
- Do pets sleep in your bed?
- Do you need a bedside commode?
- Do you need an adjustable hospital bed?
- Do any modifications need to be made in your bedroom?

NOTES:	List changes	or impro	vements	to be	made;	timeline	for	completion;	who	will b	e respo	onsible
who will f	ollow-up											

### REMEMBER - THINGS CHANGE, DO A FOLLOW-UP INSPECTION ONCE A YEAR!

### **ASSISTIVE AND SAFETY DEVICES**

As we, our loved ones, or friends grow older, we may experience some difficulty with seeing, hearing, remembering or getting around. As these changes take place, it is a good idea to make some small adjustments to our environment to help maintain or improve our quality of life, our safety and ability to perform activities of daily living.

Some simple devices can help us carry out activities of daily living more easily or with greater safety. They are called assistive devices because they can assist us with getting dressed, taking a shower, reaching out-of-the-way places, reading, writing, hearing and getting around.

Many can be "do-it-yourself", made from simple things we have at home, such as painting the "off" position on the stove with red nail polish or attaching the house key to a handle with rubber bands to make it easier to turn. The cost and availability of these helpful tools varies widely, so if you are not sure what would serve your needs, ask a health professional or health insurance provider. The cost of medically necessary devices may be covered, in whole or in part, by health insurance if prescribed by your doctor.

#### **ACITVITIES OF DAILY LIVING:**

Canes, walkers, wheelchairs, scooters. Low rise steps, ramps and threshold covers. Rails, ramps and platforms to get in and out of home, mobile homes and vehicles. Lifts to get in and out of beds. Lift-chairs to get up and down. Moving platforms to get up and down stairs. Incontinence supplies: briefs, diapers, pull-ups, bed pads. Bottom wipers. Grab bars. Hand-held showers, shower chairs, transfer benches, raised toilet seats and toilet safety frames, bedside commodes. Lever style handles, cooking and eating implements. Plates and pots with suction cups. Clothing with Velcro fasteners. Reachers and grabbers.

### **HEARING:**

Trained service animals. Analog and digital hearing aids. Telephone amplifiers with adjustable tone, pitch and volume. Flashing-light phones, doorbells and smoke alarm adapters. Cordless headphones for televisions and audio devices. Vibrating alarm clocks to place under the pillow.

#### SAFETY:

Fire alarms and extinguishers. Buzzers on exit doors and windows. Dead bolts and chain locks on exit doors. Intercoms. Motion detector lights. Emergency personal alarm system. Plastic plugs for unused electrical outlets, child safety locks. Whistles. Cordless and cell phones.

### SEEING:

Trained service animals. Glasses and magnifiers. Talking watches, alarm clocks, timers, calculators, scales and thermometers. Talking blood pressure monitors. Writing aids such as large "grips" for pens and pencils. Tactile knobs for stoves with raised dots to indicate settings. Battery lighted magnifiers for reading. Large print and audio books and tapes. Magnifiers for television and computer screens. Voice activated cell phones. Remote controls with large buttons. Computers with voice recognition software and large letter keyboards.

#### **REMEMBERING:**

Electronic pill boxes with an alarm to signal medication time. Telephones with memory dialing and spaces for photos of people. Timed faucets to automatically turn off water. Whiteboards with colored pens for notes and appointments. Computer games for memory enhancement. Exercise equipment. Crossword and jigsaw puzzles. Photo albums.

### FALL PREVENTION RESOURCES

- Arizona Fall Prevention Coalition www.azstopfalls.org
- AARP Independent Living <u>www.aarp.org/programs/connect</u>
- National Institutes of Health (NIH) Senior Health <u>www.nihseniorhealth.gov</u>
  - Has links to Exercise at www.nihseniorhealth.gov/exercise/toc.html
  - o Fall Prevention at <a href="https://www.nihseniorhealth.gov/falls/toc.html">www.nihseniorhealth.gov/falls/toc.html</a>
- . National Institute on Aging Information Center <a href="https://www.nia.nih.gov/HealthInformation/Publications">www.nia.nih.gov/HealthInformation/Publications</a>
  - Talking with Your Doctor: A guide for Older People
  - Exercise: A Guide from the National Institute on Aging
  - o Exercise: A Video from the National Institute on Aging

### Falls prevention topics:

- o Exercise and Physical Activity: Getting Fit for Life
- Falls and Fractures
- Aging and Your Eyes
- National Institute on Aging Age Page: Falls and Fractures www.nia.nig.gov/HealthInformation?publications/falls
- Centers for Disease Control and Prevention <u>www.cdc.gov/injury</u>
- National Center for Injury Prevention and Control <u>www.cdc.gov/ncipc</u>
- American Geriatrics Society Patient Education Forum <u>www.gericareonline.net</u>
- UCLA Division of Geriatrics Patient Education www.geronet,ucla/centers/acove/patient education.html
- EASY-Exercise and Screening for You www.easyforyou.info
- Journeyworks Publishing <a href="https://www.jurneyworks.com">www.jurneyworks.com</a>
- www.ehow.com/how 4889 make-simple-wheelchair
- www.howtocare.com

### 4.4. EMERGENCY PREPAREDNESS – ADDITIONAL RESOURCES

### **EMERGENCY PREPAREDNESS CHECKLIST**

(Prepared by Pima Council on Aging, Area Agency on Aging Region II, Arizona)

Most of us do not want to think about disasters or emergencies. But recovering from an emergency tomorrow may depend upon what we do today. Disasters and emergencies can take many forms, from severe weather to electrical outages, food shortages, illnesses or acts of terrorism. Use this checklist as a starting point to prepare yourself or your household for the unexpected. Responding to any unforeseen situation is easier if you are prepared. STAY CALM. You have made your plans to expect the worst, now hope for the best!

**BE INFORMED:** It is important to be informed and learn about what types of emergencies are likely to affect your region and community:

- If you have a telephone, cell phone or a computer email account, sign up for the Regional Automated Emergency Notification System. This voluntary and free service is a national reverse 911 system operated by the U.S. Department of Homeland Security. This national emergency alert system sends electronic notices about severe weather or other emergencies such as power outages, chemical spills, seasonal flooding and more. It is specific to your zip code and you can identify your home or work address. Alerts can be sent to your land phone, cell phone, email or by text messaging. Free sign up is at: <a href="www.myalerts.mystateUSA.com">www.myalerts.mystateUSA.com</a>.
- Purchase an emergency radio that operates on solar, battery or electric power.
- Read daily newspapers and listen to local TV and radio stations.
- List local contacts for Emergency Information and for first responders like police and fire departments. Each county in Arizona has a police or sheriff's department and an Office of Emergency Management. List your local numbers now. The middle of an emergency is not the best time to be looking up phone numbers!

**MAKE AN EMERGENCY SUPPLIES KIT:** What would you do if the resources you used on a daily basis were limited or unavailable, such as water, food, electricity, medical facilities, pharmacies or inhome support services? Make a kit, (perhaps in a rolling suitcase, plastic garbage can or duffle bag) of basic items that will help you be self-sufficient for 5-7 days. Make note of when perishable items, such as food, water or batteries need to be replaced:

- Radio, flashlight, extra batteries
- First aid kit
- Copies of prescriptions for medicines and glasses
- Glasses, hearing aids and batteries
- Store a gallon of water per person per day (NOTE: this is extremely heavy)
- Food ready to eat meals that do not require cooking
- Changes of clothing appropriate for season of the year
- Hat, gloves, coat, sun screen, insect repellant, umbrella
- Blankets, or sleeping bag, and pillow
- Toothbrush, toothpaste, denture cleaner, etc.
- Extra medicine (if doctor will prescribe and finances allow), insulin
- Sanitary supplies, toilet paper, paper towels, wet wipes
- Names, addresses and phone numbers of family, friends, doctors, insurance agents, coworkers, home health workers.
- Make copies of ID cards, bank account numbers, insurance cards, policy numbers, birth certificate, passport secured in a water proof container
- Keep some cash and a spare set of keys on hand
- If you drive, make sure your car has gas
- Tools can opener, screwdriver, pliers, knife, garbage bags, whistle
- Pet food, carriers, ID tags, leashes and supplies
- Other supplies personal to you such as puzzles, crosswords, books, knitting, etc.

**MAKE A PLAN, JUST IN CASE:** What would you do in an emergency? Think of the people who assist you on a daily basis. How will you contact them? Share your plans in advance. Make sure each friend or family member knows what you plan to do in an emergency. Review your plan about twice a year, when you change the perishable items in your emergency kit. Know how to turn off your utilities if you must evacuate.

- Create a personal support network. Make sure a trusted relative, neighbor or friend knows how you plan to evacuate and where you plan to go in an emergency. Make sure they have a key to your home and can help with your utilities or emergency supply kit, if needed.
- Develop a family communications plan. Decide in advance who would be the main contact, preferably an out of state person. Decide in advance what you would do under different emergency situations and discuss this with your network. Choose an area outside your neighborhood such as a library or community center in which to rendezvous.
- **Decide if you need to stay or go** based on common sense, the best available information or the recommendations of emergency responders. There may be situations when it is simply best to stay where you are and avoid going outside.
- Consider the needs of pets or service animals. Prepare for their food, water, medicines, leashes, carriers, cages or haulers. Pets may not be allowed in public shelters. Determine in advance where they can be boarded with an out of area friend or kennel.
- Finally, register with your county's Office of Emergency Management if you will require special needs assistance, either to evacuate or to shelter in place. Have extra medications or copies of your prescriptions with you and the names and phone numbers of your doctors, attendant care workers, etc.

# PREPARING FOR AN EMERGENCY: A CHECKLIST FOR PEOPLE WITH MOBILITY LIMITATIONS

Prepared by the American Red Cross

Emergencies like fires and floods can present a special challenge to everyone. The challenge of protecting oneself requires planning and oftentimes, assistance from others. This holds true for the millions of people with mobility problems as well. Protecting yourself and your family when disaster strikes requires planning ahead. This checklist will help you get started...

- First of all, get the appropriate information. Call your local American Red Cross chapter or County Emergency Management Office to find out which disasters occur in your area and how to prepare for each. Ask about special aid that may be available to you. Many communities ask people with a disability to register, usually with the County Emergency Management Office so that help can be provided quickly.
- 2. **Ask your case manager about emergency plans in your area** and what provisions have been made to assist you to evacuate if needed.
- 3. **If you have a personal care attendant obtained from an agency**, check to see if the agency has a plan for emergencies.
- 4. **Create a plan**. Meet with household members and/or your personal care attendant to discuss what measures you might have to take.
- 5. **If you or someone in your household uses a wheelchair**, make more than one exit from your home wheelchair accessible in case the primary exit is blocked. Plan and practice how to escape from your home.
- 6. Consider getting a medical alert system that will allow you to call for help if you are immobilized.
- 7. **Keep emergency telephone numbers posted near phones** and teach your children how and when to call for help.
- 8. **If you live in an apartment**, ask the management to identify and mark accessible exits and know in advance where they are located.
- 9. **Prepare a Disaster Supplies Kit.** These supplies should be stored in an easy to carry container, such as a backpack, duffel bag or wheeled suitcase.

#### Your kit should include...

- 1. Battery-powered radio, flashlight, and plenty of extra batteries
- 2. First aid kit, any prescription medicines you take (along with copies of written prescription), and an extra pair of eye glasses
- 3. Extra hearing aid batteries
- 4. Supply of water (one gallon per person per day), stored in sealed, unbreakable containers, marked with storage date (replace every 6 months)
- 5. Supply of nonperishable food and a manual can opener
- 6. Infant necessities
- 7. Extra wheelchair batteries, oxygen, medication, catheters, food for guide or service dogs or other specialty equipment you might need
- 8. Change of clothing, rain gear and sturdy shoes
- 9. Blankets/sleeping bags
- 10. List of family physicians to be notified if injured
- 11. List of the style and serial numbers of medical devices, such as pacemakers
- 12. Extra set of car keys
- 13. Cash
- 14. Personal identification and proof of residency

You should be aware of what hazards exist in your home and how they can be corrected. Repair defective electrical wiring, secure large objects, repair cracks in ceilings or foundations, and have vents

cleaned by a professional. Basically, you want to be aware of and correct any potential hazards -- anything that can move, fall, break, cause a fire or impede your mobility.

If you do need to evacuate to a shelter, confirm upon arrival that the shelter can meet any special care needs that you may require. If your shelter cannot, consider seeking an alternative shelter that can meet your needs if the situation allows.

Discuss these ideas with your family, friends, case manager and/or a personal care attendant.

### DISASTER PREPAREDNESS FOR SENIORS

Prepared by the American Red Cross

Senior citizens can protect themselves and cope with disaster by planning ahead. Knowing what to do is your best protection. First of all, it is a good idea to know which kinds of disasters are most common in your particular area. Preparing for a disaster that is likely to happen in your area will help you be prepared for any disaster. Here in Florida, we are prone to severe weather storms, such as tropical storms and hurricanes. Having a Hurricane Survival Plan is absolutely necessary. Even if you have physical limitations, you can still protect yourself by having a plan.

Staying aware of weather conditions is also very important. Listen to daily weather forecasts during hurricane season (June 1 - November 30). You should know your designated Emergency Alert System stations. As hurricanes develop, they are monitored closely by the National Weather Service. You can purchase special NOAA Weather Radios that broadcast National Weather Service warnings, watches, forecasts and other hazard information 24 hours a day. They are available at stores that sell electronics. Call your local National Weather Service office for more information.

It is also a good idea to have a disaster plan so that you can respond quickly and efficiently to an emergency. Plan and practice the best escape routes from your home. Post emergency phone numbers near the phone. Arrange to have a "contact"- someone who will call and check on you in the event of an emergency. Teach those who may need to assist you how to operate necessary equipment such as respirators. If necessary, plan on transportation if you need to evacuate to an American Red Cross shelter. Those who need assistance should register NOW with County Emergency Management. If you require oxygen, check with your supplier about emergency plans. If you evacuate, remember to take medications with you, along with written instructions regarding your care. For those senior citizens living in a nursing home, adult congregate living (ACLF) or boarding home, the administrator should be contacted to learn about the disaster/evacuation plan for that facility.

For your safety and comfort, you need to have emergency supplies packed and ready in one place before disaster hits. You should assemble enough supplies to last for at least three days. Supplies should be stored in an easy to carry container, such as a backpack or duffel bag with an identification tag attached.

### **General Emergency Supplies**

- Water supply one gallon per person per day stored in sealed, unbreakable containers that are easy to handle. It is smart to identify the storage date and replace every six months.
- Non perishable food supply- including any special foods you may require
- Battery-powered radio and flashlight with extra batteries
- o Change of clothing, rain gear, and sturdy shoes
- Blanket or sleeping bag
- Extra set of keys
- o Cash, credit cards, and change for pay phones
- Personal hygiene supplies
- Phone numbers of local and non-local relatives or friends
- Insurance agent's name and number

### **Supplies for your Medical Needs**

- First-aid kit
- Prescription medicines, list of medications including dosage, and a list of any allergies
- Extra eye glasses
- Extra hearing aid batteries
- o List of style and serial numbers of medical devices such as pacemakers
- Medical insurance and Medicare cards
- List of doctors and relative or friend who should be notified if you are injured

Going to a shelter may be necessary, especially if the disaster affects a large number of people and/or the emergency is expected to last several days. Senior citizens can best cope with the conditions in a shelter by, again, having a well-thought-out plan. If you need to evacuate, take your Disaster Supplies kit, and make sure to lock your home.

If you receive home care, coordinate with your home care provider for evacuation procedures. Don't forget to notify authorities of any special needs you may have. They will do their best to accommodate you and make you comfortable. And if you are sure you have enough time (in most cases, you should have enough time, if you stay informed), let others know when you left and where you are going. Make arrangements for pets-- they are not allowed in public shelters. And if time permits, shut off water, gas, and electricity if instructed to do so and if you know how. Gas must be turned back on by a professional.

# **Emergency Plan**<sup>70</sup>

Every individual especially if living alone should have an **Emergency Plan** posted in an obvious place such as the refrigerator. The plan should be kept up to date with <u>current</u> medications (recommend attaching it to the back of the plan) in case the individual is unable to give the paramedics the information in an emergency. Below is an example of an Emergency Plan.

EMEDGENCY DI ANI

Name:	EWERGENCT PLAN	
	Responsible Party/Emergency Contact(s)	
Name:	Phone(s):	
Name:	Phone(s):	
	911: Fire/Police/Paramedics	
Hospital Preference:		
Physician:	Phone:	
Allergies:		
Living Will: □ Yes □ No CPR: □ Yes □ No (If No, r	my orange form is located (where):	)
My Current Medication List Is	s Located (where):	
Comments:		
Signature:	Date:	

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<sup>&</sup>lt;sup>70</sup> From the *Principles of Caregiving – Fundamentals*, Arizona Direct Care Curriculum Project, 2008.

### **Websites and Other Resources**

#### In Arizona:

Arizona Department of Economic Security, <u>www.azdes.gov</u>

Division of Aging and Adult Services (DAAS), (602) 542-4446,

Home page

https://www.azdes.gov/common.aspx?menu=36&menuc=28&id=190

Policy and Procedure Manual, Alerts, and other Publications:

https://www.azdes.gov/common.aspx?menu=36&menuc=28&id=8252.

### Adult Protective Services, Central Intake

1-877-SOS-ADULT (1-877-767-2385), TDD: 1-877-815-8390, (602) 277-4984

https://www.azdes.gov/common.aspx?menuc=100&menu=620&id=1708

### **Division of Developmental Disabilities (DDD):**

Home page

https://www.azdes.gov/main.aspx?menu=96&id=2454

Policies and Procedures

https://www.azdes.gov/main.aspx?menu=96&id=2844

### Arizona Department of Health Services (ADHS), (800) 314-9243, www.azdhs.gov

Division of Licensing Services: <a href="http://www.azdhs.gov/als/index.htm">http://www.azdhs.gov/als/index.htm</a>

Division of Behavioral Health Services: http://www.azdhs.gov/bhs/index.htm

### Arizona Long Term Care System (ALTCS):

Chapter 1200 of the AHCCCS Medical Policy Manual (AMPM) covers ALTCS; there is also eligibility

manual: http://www.azahcccs.gov/reporting/PoliciesPlans/manuals.aspx

Arizona Department of Emergency and Military Affairs, (800) 411-2336, www.asdema.gov

Arizona Administrative Code (rules): http://www.azsos.gov/public\_services/rules.htm

Arizona Revised Statutes (ARS): http://www.azleg.state.az.us/ArizonaRevisedStatutes.asp

### **Nationally:**

Centers for Disease Control and Prevention, (800) 232-4636, (888) 232-6348 (TTY), www.cdc.gov

FirstGov.gov, The U.S. Government's Official Website, (800) 333-4636, www.firstgov.gov

Department of Homeland Security, (800) 327-3239, www.ready.gov and www.dhs.gov

NOTES: