



For the Lifespan: The Caregiver Guide

Module 7

Community Supports for Remaining at Home

Participant Guide

Module 7

Community Supports for Remaining at Home

PURPOSE



Module 7 is designed to teach caregivers about the community supports that will help the person they care for remain at home, despite failing health, or to return home after an illness or injury. It will teach you how to obtain help with daily, weekly, or monthly tasks. These tasks may include personal care, household chores, or other necessary tasks for maintaining the person you care for at home. Information will be included about where to apply for and locate services and/or funding to help pay for support services.

WHAT YOU WILL LEARN

After completing this module, you will be able to:

- Identify areas where you need help and create a checklist.
- Identify sources for getting volunteer help with tasks on your checklist.
- Describe the types of services you need that are available from public programs.
- Identify where and how to get services and/or funding to help pay for in-home and community support services.

This module will not cover technical questions about eligibility for public programs such as Medicare, Medicaid Waivers, Alternatives, Caregiver Support programs, or other publicly funded programs. These questions will need to be answered by an eligibility specialist for the particular program.

INTRODUCTION



This module will help you learn ways to support the person you care for to return home after an illness or injury, or to remain at home despite failing health. You may need help with tasks, including personal care, household chores, or other necessary tasks for maintaining a home. You may need relief at times from your caregiving role. These supports are necessary if you are to maintain a stable home for your family member.

This module will help caregivers identify the areas where you need help and recommend how to get it. Each person's needs are unique and complex, so there can be no single program that is likely to provide all that you need. So we will begin with a process of helping you assess your situation. Then we will provide information about where and how to get help.

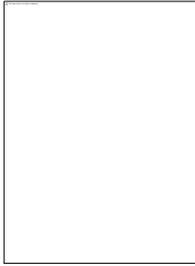
Here are Some Examples of Caregiver Situations:

Nancy is a small woman who lives with her 6'5" father with multiple sclerosis. He is no longer able to bathe himself. Nancy is afraid that he will fall in the shower.

Merle is a caregiver for his spouse Carol, who has diabetes. She is no longer able to check her own blood sugar and prepare her insulin due to a visual impairment, and Merle needs help planning healthy meals for her.

Carla cares for her brother who has AIDS. He is unable to maintain his home and yard, and the neighbors are complaining that his lawn is overgrown and unsightly.

ASSESS YOUR SITUATION



Think about the tasks that must be performed daily, weekly, and monthly to maintain the person you care for at home. Then complete the Checklist on page 5.

- Check tasks that the person you care for is unable to perform by himself/herself.
- Check tasks that the caregiver is unable to perform or finds difficult to perform.

If there are needs that you and the person you care for have that are not on the list, write them in the blank spaces on the Checklist. Once you have completed the Checklist, you are ready for the next step.

FINDING HELP FOR TASKS ON YOUR CHECKLIST

Where to get help?

- Family
- Friends
- Neighbors
- Faith-Based Organizations
- Neighborhood Groups
- Call 211
- www.UCare.utah.gov
- Aging and Disability Resource Connection (ADRC)
- Area Agencies on Aging
- Centers for Independent Living (CILs)
- Caregiver Support Programs
- Department of Veterans Affairs

Chart A: Checklist of Needs

Create a list of caregiving tasks you need help with and are willing to allow others to do while you take time for yourself.

Ask for help from family members, friends, and neighbors. Access community resources that may be available to help you.

Share your list with others so they will know what type of help you need and can choose which task they feel comfortable doing.

Care Need	Is Help Needed?	Frequency	Name of Current Helper	Identify Who Else Can Assist or Complete This Task
Respite for Caregiver	__yes__no			
Bathing Assistive devices needed	__yes__no __yes__no			
Dressing/Grooming	__yes__no			
Eating/Feeding Assistive devices needed	__yes__no __yes__no			
Toileting Assistive devices needed	__yes__no __yes__no			
Continence Need incontinence supplies	__yes__no __yes__no			
Walking/Transferring Assistive devices needed	__yes__no __yes__no			
Meal Preparation Meals on Wheels Congregate Meals Ensure, Boost, etc.	__yes__no __yes__no __yes__no __yes__no			
Housework/Laundry	__yes__no			
Medication Management Assistive devices needed	__yes__no __yes__no			
Transportation	__yes__no			
Shopping	__yes__no			
Telephone Assistive devices needed	__yes__no __yes__no			
Vision Assistive devices needed	__yes__no __yes__no			
Safety Devices/Equipment ERS System Safe Return Med Alert Bracelet Door/window alarms Other equipment	__yes__no __yes__no __yes__no __yes__no __yes__no			
Modify Home/Repairs Yard Care	__yes__no __yes__no			
Money Management	__yes__no			

Begin a conversation by showing your Checklist to your family and friends. They may want to help.

To begin, start with your family, friends, and groups of which you are a member, such as a faith-based organization or other neighborhood groups. You should explore the willingness of those closest to you to assist you and the person you care for before going to public agencies. Why? Because they most likely want to help. They want to support you in the goal of helping your care recipient remain at home. Perhaps you have never asked for help because you didn't want to be a burden on others. Most people like helping. You may find that people are very willing to help you in small or large ways that you did not expect. They probably do not know what you need or want to intrude. So you need to ask and be prepared to respond when someone asks you if there is something they can do for you. Have a list prepared of the things that you need help with.

You may consider having a family meeting to discuss the needs of the person you care for. A "family meeting" is an opportunity for spouse, children, and others to discuss the care of a family member. This meeting focuses on the needs of the person receiving care and of the primary caregiver. It is a time to identify needs, to share responsibilities, and to come up with a plan with assignments that will best serve the care recipient.

Helpful Hints: Use respectful listening and keep an open mind. There will be differences in opinions, values, and relationships.

- Listen to the family member needing care. Talk directly to him/her and provide extra time for their response.
- Express your needs, feelings, and concerns. Do not speak for others.
- No interrupting or side conversations.
- Turn off cell phones, radio, and T.V.

- Stay focused on the purpose of “helping the person you care for maintain independent living for as long as possible” or “planning for a move”.
- Avoid using “always” or “never”.
- Give everyone an opportunity to be heard.
- Avoid making assumptions. Ask questions to get the facts.
- Remember that your family member has the right and responsibility to make his or her own decisions, if appropriate, and they are capable of doing so.

Before the Family Meeting

- Ask both the person receiving care and the primary caregiver whom they want to attend.
- Consider all relevant family members, friends, neighbors, and professionals.
- Pick a convenient date, time, and place. Arrange a conference call if possible for those who cannot attend.
- List issues to be discussed based on the goals of the person receiving care and the primary caregiver. Issues may include: help with household tasks, home safety, medical needs, caregiver stress and workload, end of life decisions, legal and financial management.
- Keep the agenda short so each issue receives full attention, and allow time to discuss next steps.
- Collect information that maybe helpful, such as medical reports or legal documents.
- Consider a professional (social worker, care coordinator, geriatric care manager, or clergy member) to facilitate the meeting if needed.

The Family Meeting

- Arrange seating so all can see and hear each other. Agree on a person to act as spokesperson and lead the meeting.
- Start the meeting with a welcome.
- Select a person to take notes on decisions, assignments of tasks, and follow-up items.
- Review the agenda and use it to stay on task.
- Address the most important issues first so they receive full attention.
- Reach a sense of closure on each issue.
- Put issues that arise during the meeting and do not get addressed in a “parking lot” to be addressed later.
- Create a plan that includes what needs to be done and who will do it. (Use your Checklist of Needs).
- Include a backup plan in case of an emergency.
- Summarize the discussion and review all decisions made.
- Identify a family spokesperson who will communicate the decisions to non-family members such as home care, physicians, and others.
- Plan the next meeting if needed.

Follow-Up

- If the care receiver agrees, share the plan with those who need to know, such as family members, health care workers, or your physician.
- Stay connected through mail, phone calls, e-mail, or a website.

Although family meetings are hard, they are a good way to pull together and support the person you care for. Don't be afraid to ask

for help with family meetings from a health care professional, social worker, or clergy member. Don't expect that everything will be solved all at once. Providing care is an ongoing task. Pulling the family together to provide that care may also be an ongoing process. For more information on holding a family meeting, visit the Family Caregiver Alliance website at www.caregiver.org.

One way to begin a conversation would be to show your completed "Checklist of Needs". This provides a nice way for them to pick tasks that they like to do and for you to get the help you need. It becomes a real win-win for everyone involved. You get help. Your helpers get satisfaction from helping.

If your family and friends are doing all they can, you need to branch out beyond your inner circle and contact community organizations that can help. Which ones you contact will depend on the kind of help you need. For example, someone from your faith-based organization may be able to provide respite or go grocery shopping for you. Perhaps the neighborhood scouts could help with spring or fall yard cleanup. Your neighbor may be willing to launder your sheets and towels when she does her own.

If none of these strategies gets you the help you need, or if there are still things on your list that you can't get help for, you can look for agencies that have programs for specific kinds of services. Maybe some of the things on your list require special skills. 211 offers statewide information and referral. Probably the best place to start is with your local Area Agency on Aging and Center for Independent Living. A description of their services and statewide contact information is listed at the end of your Guide, along with other resources.

There are pros and cons of using agency services.

ADVANTAGES OF USING AGENCY SERVICES

- Provide you with a needed break.
- Relieve you of tasks that you are not comfortable doing or tasks you don't know how to do.
- Prevent or postpone institutionalization for the person you care for.
- Relieve the person you care for from feeling like a burden.

RELUCTANCE TO USE AGENCY SERVICES

- Caregivers may feel like they are not doing their duty.
- Don't want to use government services.
- Privacy concerns.
- Bureaucratic hassles.
- Don't know what services are offered.

If you make the decision to request assistance from an agency, your care recipient will have to meet the qualifications set by the agency or funding source.

Refer to your Checklist. There are different resources available depending on what you need. Agency funding is usually tied to different types of needs. It's helpful to understand the following five categories of in-home services.

CATEGORIES OF IN-HOME SERVICES

- Home Health
- Personal Care
- Homemaker/Chore
- Respite Care
- Hospice

Look on page 14 for the chart titled "Guide to In-Home Supports."

The Chart is a summary of the information described below. As you

work with agencies, you may find that some terms are not familiar. The Glossary on pages 40-46 will help you better understand their terms.

1. Home Health Services



Home health services are typically approved by a physician and supervised by a health professional such as a nurse. The services are provided in a person's home by a licensed health professional that is qualified to perform the tasks needed by the patient. The home health professional may oversee wound care, transfusions, chemotherapy, or ostomy care. A registered nurse (RN) may administer wound care or replace catheters. Licensed therapists, such as a physical or occupational therapist, may supervise therapies in the home. A certified nursing assistant (CNA) may provide hands-on assistance such as bathing or dressing, or stand-by assistance such as reminding a patient to take their own medications.

2. Personal Care Services



Personal care services (also called in-home services, personal attendant, personal assistance services or PAS) can help with “activities of daily living” (ADL), such as bathing, toileting, getting dressed, or eating. PAS may also provide help with “instrumental activities of daily living” (IADL), such as meal preparation, shopping, and housekeeping. You may be able to hire a friend, neighbor, or another family member to do these things for the person in need. You are not permitted to hire the spouse of the Medicaid recipient with Medicaid funds. You can locate personal attendants through a home health agency.

Some PAS services are “participant-directed” which means that the individual has control over the hiring, supervision, and retention of the personal attendant, including approval of the attendant's time

sheet. If the person is unable to direct his or her own personal attendant, another person may be appointed to help in the supervision. Refer to Module 8 for more information about hiring a personal attendant or working effectively with in-home service providers.

Another service category called “companion services” can be used to support community activities to prevent isolation of the person. Companion services may assist with such tasks as cooking, shopping, and getting to appointments for a person who is unable to do these things for themselves. The housekeeping or other supports must be incidental to providing companionship and not the primary purpose of the visit.



3. Homemaker/Chore Services

Homemaker services are “light” household activities such as meal preparation, laundry, and routine household care. Homemaker services are provided to maintain a clean and sanitary living environment for the individual.

Chore services are “heavier” housework such as washing floors or walls, shoveling snow, or making repairs to make the home safe. These services are provided to help seniors and people with disabilities remain in their homes. Providers of these services must have a current business license that permits them to provide the services.

4. Respite Care

Respite care services are “relief” for the caregiver. Respite care can be provided in the home to give the caregiver a break from their caregiving responsibilities. Respite care may be provided by a companion, a neighbor, or a personal attendant from an agency. As

with the home health and personal attendant services, individuals must pass a criminal background check in order to provide these services. Respite may also be provided outside the care receiver's home, such as an adult day program for a few hours, or a residential care facility overnight or for several days.

5. Hospice



Hospice services provide special care for individuals who are near the end of their life and for their families either at home, a special facility, or a hospital. Hospice provides comfort rather than lifesaving heroic measures. The services address the emotional, social, financial, and spiritual needs of individuals who are terminally ill and their families. Services are provided by a hospice team and include comprehensive medical management, comfort care, education, and spiritual counseling.

Hospice providers are certified by Medicare and licensed by the state to provide the comprehensive range of services needed by the individual and care recipient. A physician makes the determination of when hospice services are needed, and the individual and/or a family member choose hospice care.

Chart B: Guide to In-Home Supports

	What Tasks Do They Help With?	Who Can Provide?
Home Health Services	Nursing services such as dressing wounds, changing catheters, or therapy services. These services are temporary or short-term.	Licensed health professionals ²
	Hands-on or stand-by assistance with activities of daily living, such as bathing, dressing, reminders to take medications.	Certified Nursing Assistant (CNA) ² Private duty/private pay
Personal Care or In-Home Services	Personal attendant services are <i>participant-directed</i> help with personal care such as bathing, dressing, cooking, and eating.	Friend, family member ¹ , home health worker ² Private duty/private pay
	Companion services support community activity and prevent social isolation, and can help with cooking, laundry, shopping.	
Homemaker / Chore Services	Homemaker services are “light” household tasks such as cooking, cleaning, laundry.	Friend, family member ¹ , trained homemaker ³ Private duty Personal care agency
	Chore services are “heavier” household tasks such as washing floors or walls, yard care, snow removal.	Neighbor, chore service agency ³ Private duty Personal care agency
Respite Care Services	In home relief for caregiver.	Family member ¹ , friend ² Private duty Personal care agency
	Out of home stay.	Licensed facility
Hospice	Nursing services, personal care, social services, physician visits, counseling, homemaker services, pastoral care. Hospice care can be reassessed and patient can be placed back on home health.	Hospice team (physicians, nurses, social workers, clergy, volunteers)
		Licensed hospice facility or hospital

¹ Spouse cannot be paid to provide services under Medicaid

² Need a criminal background check and current first aid certification

³ Must have current business license to provide the service

TO FIND OUT ABOUT HOME HEALTH SERVICES

- Contact your health plan first.
- Locate a home health agency on the Utah Department of Health website: <http://health.utah.gov/hflcra>. Click on Facility Info, then Listing by County, or call 800-662-4157.
- Call the Utah Association for Home Care at 801-487-8242 or go to <http://ua4hc.org>.
- Call 211 statewide or go to www.UCare.utah.gov.



If the person you care for is being treated for a medical condition, his or her health care provider is the first place to start. Your care recipient's doctor or health plan can recommend a home health agency. Your health plan may have a contract with a particular home health agency and may be required to use that agency in order for the plan to pay. Medicare, Medicaid, and other health insurance plans may pay for home health services on a short-term basis if your doctor states it is medically necessary.

The Home and Community-Based Alternative program and the Medicaid Aging Waiver program may provide home health services on a longer term basis to prevent the person from having to go to a nursing home. The Utah Caregiver Support Program provides short-term, temporary support to caregivers through the local Area Agencies on Aging. Each of these programs has different rules for eligibility and requires an assessment to be performed by a case manager.

If you don't have insurance and can pay privately, contact a home health agency or non-medical agency directly. They are listed in the yellow pages or you can call the state Health Facility Licensing Bureau, 800-662-4157, or visit <http://health.utah.gov/hflcra> to get a list of licensed home health agencies in your area. If you go to

www.medicare.gov you will find “report cards” for home health agencies and LTC Facilities.

WHERE TO FIND OUT ABOUT OTHER IN-HOME SERVICES

The first place to start to learn more about finding in-home services is your local Area Agency on Aging (AAA).

- Contact your local Area Agency on Aging 877-424-4640 or www.hsdaas.utah.gov or Utah Division of Aging
- Aging Disability Resource Connections 801-585-6361 or <http://www.utadrc.org> 801-587-9620
- Centers for Independent Living
<http://www.ilru.org/html/publications/directory/utah.html>
- Veterans Caregiver Support Services 855-260-3274
www.caregiver.va.gov
- U.S. Department of Veterans Affairs www.va.gov or
<https://www.ebenefits.va.gov/ebenefits-portal/ebenefits.portal>
- Utah Association for Home Care at 801-487-8242 or go to www.ua4hc.org
- Utah Division of Services for People with Disabilities, Physical Disability Waiver program 800-837-6811 or www.hsdspd.utah.gov
- Alzheimer’s Association Help Line 800-222-3900
- UCare 211
- www.ucare.utah.gov
- Hospice Services in Utah 801-892-0155
- www.leaving-well.org
- www.Medicare.gov

- Ask about VA Aid and Attendance program administered by the VA
- Disability Support Center for Families, Amy Notwell
1574 West 1700 South, Suite 1A
Salt Lake City, UT 84104
801-973-0206

Description of Services

Area Agencies on Aging: The first place to start to learn more about in-home services is your local Area Agency on Aging (AAA). These agencies are an excellent source of information about community programs, including personal care, homemaker, and respite care. Whether you are able to pay for the services yourself or are looking for financial assistance, the AAA has specialists who can provide information. The AAA administers several programs that provide funding for community supports for low-income individuals or adults with disabilities as well as for seniors.

Utah Aging and Disability Resource Connections: ADRC programs provide information and assistance to individuals needing either public or private resources, professionals seeking assistance on behalf of their clients, and individuals planning for their future long-term care needs. ADRCs target services to seniors and people with disabilities (i.e., individuals with physical disabilities, serious mental illness, and/or mental retardation/developmental disabilities). The ADRC works towards the goal of serving all individuals with long-term care.

Centers for Independent Living: CILs are local not-for-

profit service and advocacy organizations that help people live more independently through information and referral, peer counseling, independent skills training, and advocacy. CILs are non-residential, community-based, cross-disability organizations. They serve all people with disabilities regardless of age, gender, race, disability, and religion.

Veterans Caregiver Support Services: VA offers a number of services specifically for caregivers that can provide the support that's right for you. Whether you and the Veteran you care for could use some help at home or you just need someone to listen, we're here to help.

Department of Veterans Affairs: VA administers a variety of benefits and services that provide financial and other forms of assistance to Service members, Veterans, their dependents and survivors.

Utah Association for Home Care: An organization of home health agencies dedicated to the well-being of individuals receiving home health care and their families. They provide education for agencies and their managers, staff, and the public to help increase knowledge, skills, and the overall quality of care.

Utah Division of Services for Persons with Disabilities: DSPD provides support for persons with disabilities to lead self-determined lives. They oversee home and community-based services for approximately 4,000 people with disabilities. Support includes community living, day services, supported employment services, and support for people with disabilities and their families.

Utah Chapter of the Alzheimer’s Association: The Alzheimer’s Association Utah Chapter has service centers throughout Utah, allowing them to better serve individuals, caregivers, and families coping with Alzheimer’s disease and related disorders.

UCare: A Utah information and referral center with comprehensive information about community services that provide support and resources for caregivers and their families. UCare sponsored this training. Their website is www.ucare.utah.gov.

Hospice in Utah: The Leaving Well Coalition exists to ensure every person in Utah has the opportunity to live well to the end of life by sharing the conversation about their values, making their wishes known, and receiving the end-of-life care they desire.

INFORMATION ABOUT ELIGIBILITY FOR PUBLIC PROGRAMS

- See an eligibility specialist at the particular agency.



This training is intended to provide general information about the kinds of services that are available to support a person in the community. Detailed information about eligibility for the different programs will not be provided. That is the job for the eligibility specialists at the various agencies. This training prepares you to explain your needs to others and understand the kinds of services that are available to help you and your care recipient. Refer to the individual agencies listed in the Resource section starting on page 36 and listed above.

Look at page 35 for the chart titled “Public Funding for Community Supports.” This Chart lists services down the left column, and the public programs that provide community supports across the top.

The dots show which services are covered by the different funding sources, including Medicare, Medicaid, the Medicaid Waiver program, the Home and Community-Based Alternatives program, and the Utah Caregiver Support program.

MEDICARE



- Medicare does not pay for long-term care.

You will notice on Chart C that Medicare only pays for home health services, medical equipment and supplies, and hospice. Medicare will only pay for a licensed health professional to provide home health services when it is determined to be medically necessary on a short-term basis. Medicare will provide hospice services if the physician states the individual has less than six months to live. Medicare does not provide long-term in-home care or nursing home care.

MEDICAID

- Medicaid is for people who have low-income and low-assets.
- Must either have a disability or be 65 years of age or older.

If an individual has assets over the limit, they must use their resources to pay for their medical care until their assets are below the limit. The Medicaid program is different in every state, so be sure you get information about Utah Medicaid. You may apply for Medicaid at the Utah Department of Health or Department of Workforce Services that has offices statewide. Information is available online at www.health.utah.gov/medicaid. Call the Medicaid Information Line at 1-800-662-9651 for more information.

MEDICAID AGING WAIVER

- The Medicaid Aging Waiver allows persons to have greater income and assets than regular Medicaid.

The waiver is designed to provide services statewide to help older adults remain in their homes or other community-based settings.

The Medicaid Waiver program pays for in-home services if: 1) an individual qualifies for Medicaid and 2) would need to go in a nursing home if they didn't receive services in their home. The Medicaid Aging Waiver is different from regular Medicaid because if a person is eligible for a nursing home, the program allows them to have more income and assets, and exempts income from a spouse if they are living with the person. Eligible individuals receive all of the standard Medicaid benefits as well as the additional benefits of the Aging Waiver. Your local Area Agency on Aging (AAA) takes applications for the Medicaid Aging Waiver.

THE HOME AND COMMUNITY-BASED ALTERNATIVES PROGRAM



- Person must be at-risk for a nursing home placement.

To be eligible to participate in the program, a person must:

- 1) Be 18 years of age or older,
- 2) Be at-risk of nursing home placement,
- 3) Have health and personal needs which can be adequately met in the community within established cost limits, and
- 4) Have low-income and minimal assets. Services are based on a care plan developed by a case manager.

Financial eligibility for the Alternatives program is determined by the Area Agency on Aging case manager. Individuals who qualify for the program may be required to pay a small fee based on a

sliding fee schedule. This state-funded program limits how much can be spent for each individual.

Contact Information:

Local Area Agency on Aging or Division of Aging and Adult Services
195 North 1950 West
Salt Lake City, UT 84116
Phone: 801-538-3910 or 877-424-4640, **Email:** daas@utah.gov

THE UTAH CAREGIVER SUPPORT PROGRAM

The Utah Caregiver Support Program provides information, assistance, support, caregiver training, and counseling to:

- 1) caregivers of adults 60 years of age or older; or
- 2) caregivers 60 years of age or older caring for persons with mental retardation or related developmental disabilities; or
- 3) adult family members (age 18 years or older) or other adult informal caregivers providing care to individuals of any age with Alzheimer's disease and related disorders; or
- 4) grandparents or older individuals (not biological or adoptive parents) 55 years of age or older who are a relative caregiver of a child not more than 18 years of age; or
- 5) grandparents and other relatives (not biological or adoptive parents) 55 years of age and older providing care to adults, age 18 to 59 years, with disabilities.



This program is a good resource for information about in-home supports for individuals who have resources to pay privately, but who need information about where to find providers, help with care planning, counseling, etc. The program also provides respite and supplemental services to caregivers of adults over 60 who are

unable to perform at least 2 activities of daily living. Eligibility is determined through an assessment process performed by a case manager.

Contact Information:

Local Area Agency on Aging or Division of Aging and Adult Services
195 North 1950 West
Salt Lake City, UT 84116
Phone: 801-538-3910 or 877-424-4640, **Email:** daas@utah.gov

NEW CHOICES WAIVER

Purpose



This waiver is designed to serve people who meet nursing facility level of care and who have been residing long-term in a nursing facility or assisted living facility. The program provides supportive services to enable individuals to live in their own homes or in other community-based settings.

Eligibility Requirements

- Must be at least 18 years old;
- The primary condition must not be attributable to a mental illness;
- The individual does not meet ‘Intensive Skilled’ level of care criteria; and
- The individual does not meet level of care criteria for admission to an intermediate care facility for people with intellectual disability (ICF/ID).

In addition, eligible individuals must be:

- Receiving Medicaid reimbursed nursing facility care on an extended stay basis of 90 days or more; or

- Currently receiving Medicare reimbursed care in a licensed Utah medical institution (that is not an institution for mental disease), on an extended stay of at least 30 days, and will discharge to a Medicaid certified nursing facility for an extended stay of at least 60 days; or
- Receiving Medicaid reimbursed services through another of Utah's 1915(c) waivers and have been identified as in need of immediate or impending nursing facility care; or
- Residing in a licensed assisted living facility on an extended stay of 180 days or more.

Limitations

- Serves a limited number of individuals (1,400).
- Individuals can use only services assessed as needing.

Waiver Services

- Adult Day Care
- Adult Residential Services
- Assistive Technology Devices
- Attendant Care
- Caregiver Training
- Case Management
- Chore Services
- Consumer Preparation Services
- Emergency Response Systems
- Environmental Accessibility Adaptations
- Financial Management Services
- Habilitation Services
- Home Delivered Meals
- Homemaker Services

- Community Transition Services
- Medication Assistance Services
- Non-Medical Transportation
- Personal Budget Assistance
- Respite Care
- Specialized Medical Equipment
- Supportive Maintenance

Contact Information:

Contacts from the Salt Lake City area:

801-538-6155, option 6

Outside of the Salt Lake City area and neighboring states:

800-662-9651, option 6 **Email:** newchoiceswaiver@utah.gov

ACQUIRED BRAIN INJURY WAIVER

Purpose



This waiver is designed to help people with an acquired brain injury to remain in their homes or other community-based settings statewide. Individuals are able to live as independently as possible with supportive services provided through this waiver.

Eligibility Requirements

- Be 18 years of age or older.
- Have a documented brain injury.
- Require nursing facility level of care.
- Meet financial eligibility requirements for Medicaid.
- Primary condition cannot be attributable to a mental illness.

Limitations

- Serves a limited number of individuals.
- There is a waiting list to get on this waiver.

- Individuals use only services they are assessed as needing.

Waiver Services

- Chore Services
- Community Living Supports
- Companion Services
- Family Assistance and Support
- Homemaker Services
- Non-Medical Transportation
- Personal Emergency Response System
- Respite Care
- Specialized Medical Equipment
- Structured Day Program
- Support Coordination
- Supported Employment

Contact Information:

Division of Services for People with Disabilities
195 North 1950 West
Salt Lake City, UT 84116
Phone: 801-538-4200, **Email:** dspd@utah.gov

AGING WAIVER

Purpose

This waiver is designed to provide services statewide to help older adults remain in their homes or other community-based settings. Individuals are able to live as independently as possible with supportive services provided through this waiver program.

Eligibility Requirements

- Be 65 years of age or older.

- Require nursing facility level of care.
- Meet financial eligibility requirements for Medicaid.

Limitations

- Serves a limited number of individuals.
- Individuals only use services they are assessed as needing.

Waiver Services

- Adult Companion Services
- Adult Day Health Services
- Case Management
- Chore Services
- Emergency Response Systems
- Environmental Accessibility Adaptations
- Fiscal Management Services
- Home Delivered Supplemental Meals
- Homemaker Services
- Medication Reminder Systems
- Non-Medical Transportation
- Personal Attendant Program Training
- Personal Attendant Services
- Respite Care Services
- Specialized Medical Equipment
- Supportive Maintenance Home Health Aide

Contact Information:

Division of Aging and Adult Services
195 North 1950 West
Salt Lake City, UT 84116
Phone: 801-538-3910, **Email:** daas@utah.gov

PHYSICAL DISABILITIES WAIVER



Purpose

This waiver is designed to provide services statewide to help people with physical disabilities remain in their homes or other community-based settings. Individuals are able to live as independently as possible with supportive services provided through this waiver program. It is designed to be consistent with a service delivery system that promotes and supports participant self-determination.

Eligibility Requirements

- Be 18 years of age or older.
- Have a physician certify the physical disability of the individual.
- Have a physical impairment resulting in the functional loss of 2 or more limbs, and requiring at least 14 hours per week of personal assistance.
- Be capable of supervising, training, and managing his/her attendant.
- Be capable of managing his/her own financial and legal matters.
- Require nursing facility level of care.
- Meet financial eligibility requirements for Medicaid.
- Have at least one personal attendant trained (or willing to be trained) and available to provide the authorized waiver services in a residence that is safe and adequately equipped for care of the individual.

Limitations

- Serves a limited number of individuals

- There is a waiting list to get on this waiver
- Individuals can use only those services they are assessed as needing

Waiver Services

- Consumer Preparation Services
- Financial Management Services
- Local Area Support Coordination Liaison
- Personal Assistance Services
- Personal Emergency Response System

Contact Information:

Division of Services for People with Disabilities
195 North 1950 West
Salt Lake City, UT 84116
Phone: 801-538-4200; **Email:** dspd@utah.gov

COMMUNITY SUPPORTS WAIVER

Purpose



This waiver is for individuals with intellectual disabilities or other related conditions. It is designed to provide services statewide to help persons with intellectual disabilities (mental retardation), or persons with conditions related to intellectual disabilities remain in their homes or other community-based settings. Individuals are able to live as independently as possible with support services provided through this waiver program.

Eligibility Requirements

- Must demonstrate functional impairments in 3 or more of the 6 major areas of life activities.

- Onset of condition must occur before age 18 for mental retardation.
- Onset of condition must occur before age 22 for other related conditions.
- Primary condition must not be attributable to a mental illness.
- Meet level of care criteria for admission to an intermediate care facility for people with mental retardation (ICF/MR).
- Meet financial eligibility requirements for Medicaid.
- There are NO age restrictions for this waiver.
- Must be able to live safely in the community.

Limitations

- Serves a limited number of individuals
- There is a waiting list to get on this waiver
- Individuals can use only those services they are assessed as needing

Waiver Services

- Behavioral Consultation
- Chore Services
- Companion Services
- Day Supports
- Emergency Response Systems
- Environmental Adaptations
- Extended Living Supports
- Family/Individual Training and Preparation
- Financial Management Services
- Homemaker Services
- Living Start-up Costs

- Massage Therapy
- Medication Monitoring
- Non-Medical Transportation
- Personal Assistance
- Personal Budget Assistance
- Residential Habilitation
- Respite Care
- Specialized Medical Equipment
- Supported Employment
- Supported Living
- Waiver Support Coordination

Contact Information:

Division of Services for People with Disabilities
 195 North 1950 West
 Salt Lake City, UT 84116
Phone: 801-538-4200, **Email:** dspd@utah.gov

EMPLOYMENT-RELATED PERSONAL CARE SERVICES (EPAS)

Purpose



This program provides eligible individuals with personal care services in order to maintain employment. Services are designed to help people with disabilities work in integrated and competitive employment settings. Services may include physical assistance and cognitive cuing to direct self-performance of necessary activities.

Eligibility Requirements

- Eligible for Traditional Medicaid.
- Have a disabling condition as defined by Social Security.
- Individual must be working or have a promise of a job (at least 40 hours per month) making minimum wage or above.

- Demonstrate a need for personal care services (assessment provided).
- Complete an application for services.

Limitations

Services are **not** covered:

- When provided by a legally responsible family member or guardian
- When provided to individuals residing in hospitals, nursing facilities, or ICFs/MR
- When provided to individuals enrolled in a 1915(c) Home and Community-Based Waiver

Services

- Service Coordination
- Personal Attendant Services (ADL's)
 - Mobility/Ambulation
 - Dressing
 - Eating
 - Personal Hygiene
 - Bathing
- Personal Attendant Services (IADL's)
 - Meal Preparation
 - Ordinary Housework
 - Laundry
 - Managing Finances
 - Managing Medications
 - Shopping
 - Transportation for Work
 - Financial Management Services

Contact Information:

Patricia Wilkinson
Long-Term Care Bureau
288 North 1460 West
PO Box 143112
Salt Lake City, UT 84114-112
Phone: (801) 538-6955; **Fax:** (801) 323-1588;
Email: pwilkinson@utah.gov

MEDICALLY FRAGILE /TECHNOLOGY DEPENDENT CHILDREN



This Utah Medicaid Waiver program assists medically fragile children (up to age 21) to remain in their own homes rather than being placed in an institution. There is a limit on the number of children allowed into the waiver program. Applications are taken through the Division of Family Health Services case manager. None of the parent's income or assets is counted in considering the child's eligibility. Also, an intensive service plan is written for the child, and all services are paid by Medicaid. To be eligible for this program, children must meet specific medical criteria. The income standard, after allowable deductions, is 100% of the Federal Poverty Level, which is typically adjusted annually. All of the child's income counts. The Federal Poverty Level is available on the Internet at <http://aspe.hhs.gov/poverty>.

VETERANS

The VA offers services for caregivers. The VA also offers financial benefits and other services to support service members, veterans, and their families. Call 800-827-1000 to inquire about Veterans programs and benefits, or check www.va.gov or www.ebenefits.va.gov/ebenefits-portal/ebenefits.portal. Veterans Caregiver Support Services, www.caregiver.va.gov.

PRIVATE PAY



Many individuals and families have resources to pay for in-home support services but do not know where to get the information. They may need assistance with care planning, counseling, and support to navigate the many providers, agencies, and programs. Some private pay companies provide homemaking, personal care, companion services, medication reminders, and wellness checks. Some will reduce the rate per hour if they come 2 or more hours a visit. Some agencies provide up to 24 hour care. You can also hire private individuals. The UCare Module 8, Working Effectively with In-Home Service Providers, has more information on hiring individuals. Again, your local Area Agency on Aging is a good place to start to find out about private pay companies and services in your area. The Utah Caregiver Support Program provides information and counseling through the local Area Agencies on Aging to individuals regardless of their ability to pay. Private care managers can also help plan, locate, and arrange services for a fee.

SUMMARY

In this class you have learned about community supports that are available to help your family member to remain at home despite failing health or to return home after an illness or injury. You learned to use a checklist to identify tasks with which you need help. You learned some strategies for getting help with tasks on your checklist from friends or neighbors. And finally, you learned about some public programs where you may be able to get services and funding to help pay for in-home and community support services.

Chart C: Public Funding for Community Supports

	Medicare	Medicaid	Medicaid Aging Waiver	Alternatives Program	Utah Caregiver Support Program
Home Health – Licensed Health Professional	•	•			
Home Health – CNA	•	•	•	•	•
Personal Attendant Service		•	•	•	•
Companion Service			•	•	•
Homemaker Service			•	•	•
Chore Service			•	•	•
Respite Care Service			•	•	•
Fiscal Management Service			•	•	
Transportation		•	•	•	
Medical Equipment and Supplies	•	•	•	•	•
Case Management		•	•	•	•
Adult Day Care		•	•		•
Individual Counseling		•			•
Support Group		•			•
Home Delivered Meals			•	•	
Hospice	•	•			

REMEMBER



Remember that you don't have to do it all. It's okay to ask for help. There are community support programs that can help you. Remember to take good care of yourself by staying positive, exercising regularly, getting enough rest, eating nutritiously, using good body mechanics, keeping a sense of humor, relaxing, and doing something enjoyable when you can. Always believe in yourself and your abilities. Remember that you have the strength, courage, compassion, power, and wisdom to succeed.

Resources

UTAH AREA AGENCIES ON AGING

Bear River Area Agency on Aging (Box Elder, Cache, and Rich Counties)

170 North Main

Phone: 435-752-7242

Logan, UT 84321

Website: www.brag.utah.gov

Davis Co Health Dept., Family Health & Senior Services Division (Davis Co)

22 South State Street

Phone: 801-525-5050

Clearfield, UT 84015

Website: www.daviscountyutah.gov

Five-County Area Agency on Aging (Beaver, Garfield, Iron, Kane & Washington Co)

1070 West 1600 South, Bldg. B

Phone: 435-673-3548

St. George, UT 84770

Website: <http://www.fcaog.state.ut.us>

Mountainland Dept. of Aging and Family Services (Summit, Utah, and Wasatch)

586 East 800 North

Phone: 801-229-3800

Orem, UT 84097-4146

Website: www.mountainland.org

Salt Lake County Aging Services (Salt Lake County)

2001 South State, #S1500

Phone: 385-468-3210

Salt Lake City, UT 84190-2300

Website: www.aging.slco.org

San Juan County Area Agency on Aging (San Juan County)

117 South Main (P.O. Box 9)

Phone: 435-587-3225

Monticello, UT 84535-0009

Website: www.sjbaaa.org

Six-County Area Agency on Aging (Juab, Millard, Piute, Sanpete, Sevier, & Wayne)

250 North Main (P.O. Box 820)

Phone: 435-893-0700

Richfield, UT 84701

Website: www.sixcounty.com

Southeastern Utah Area Agency on Aging (Carbon, Emery, and Grand Counties)

Technical Assistance Center

Price, UT 84501

375 South Carbon Avenue

Phone: 435-637-4268 or 5444

P.O. Box 1106

Website: <http://www.seualg.utah.gov>

Tooele County Division of Aging and Adult Services (Tooele County)

151 N Main St. Ste 200

Phone: 435-843-4110

Tooele, UT 84074

Website: www.co.tooele.ut.us/aging.htm

Uintah Basin Area Agency on Aging (Daggett and Duchesne Counties)

330 East 100South

Phone: 435-722-4518

Roosevelt, UT 84066

Website: www.ubaog.org

Council on Aging (Uintah County)

330 South Aggie Blvd.

Phone: 435-789-2169

Vernal, UT 84078

Website: <http://co.uintah.ut.us>

Weber County Area Agency on Aging (Morgan and Weber Counties)

237 26th Street, Suite 320

Phone: 801-628-3770

Ogden, UT 84401

Website: www.weberhs.org/home

INDEPENDENT LIVING CENTERS

Active Re-Entry

10 N. Fairgrounds Rd

Price, UT 84501

Voice/TTY: (435) 637-4950

Active Re-Entry Satellite Offices

Moab Satellite Office

125 West 200 South Room 106B

P.O. Box 122

Voice/TTY: 435-259-0245

Vernal Satellite Office

520 North 2500 West

Vernal, UT 84078

Voice/TTY/fax: 435-789-4021

Ability First of Utah

491 Freedom Blvd

Provo, UT 84601

Voice/TTY: 801-373-5044

Utah Independent Living Center

3445 South Main Street

Salt Lake City, UT 84115-4453

Voice/TTY: 801-466-5565

Options for Independence

106 East 1120 North

Logan, UT 84321

Voice/TTY: 435-753-5353

Options Satellite Office

Brigham City Satellite Office

1080 North Main Street, Suite 105A

Voice/TTY: 435-723-2171

Red Rock Center for Independence

515 West 300 North Suite A

St. George, UT 84770

Iron and Garfield Counties

435-704-4798

Piute, Sevier, and Wayne

Voice/TTY: 435-673-7501

435-979-6416

Toll Free: 800-355-2195 (Utah Only)

Tri County Independent Living Center of Utah

2726 Washington Blvd

Ogden, UT 84401

Voice 801-612-3215; Fax/TTY: 801-612-3732

Websites

www.ucare.utah.gov

www.nfcacares.org

www.caregivers.com

www.eldercare.gov

www.eldercarelink.com

www.strengthforcaring.com

www.aarp.org/families/caregiving

www.caregiver.org

www.aoa.gov

www.caremanager.org

www.respitelocator.org

GLOSSARY of COMMONLY USED TERMS

The glossary will help you better understand terms commonly used by health care professionals. It also provides brief descriptions of some available programs.

Activities of Daily Living:

A term often used by healthcare professionals to assess the need and/or type of care a person may require to perform personal care activities necessary for everyday living, such as eating, bathing, grooming, dressing, and toileting.

Adult Day Services:

A supervised setting in which health and social services are provided on an intermittent basis to ensure the optimal functioning of the participant. Adult day services are generally four or more hours per day.

Area Agency on Aging:

Area Agencies on Aging (AAA) were created by Congress as part of the Older Americans Act in 1965. They are public or private non-profit agencies, designated by the state to address the needs of persons 60 years and older at the local level.

Area Agencies on Aging provide information and assistance for seniors and their families to help access community services. They also administer programs for senior citizens, disabled adults, and family caregivers to maintain their health and independence in their homes and communities. There are Area Agencies on Aging throughout the country and 12 in the State of Utah.

Care Plan:

A written plan which contains a description of the needs of the client, services necessary to meet those needs, provider of those services, funding sources, and goals to be achieved.

Centers for Independent Living:

Utah is served by six Centers for Independent Living (CILs), that work to assure that people with disabilities have physical and programmatic access to housing, employment, transportation, recreation, health, and social services.

<http://www.ilru.org/html/publications/directory/utah.html>

Chore Services:

Services needed to assist in providing a clean, sanitary, and safe environment, such as deep cleaning, repair of tile, walls and flooring, snow removal, or lawn care.

Home and Community-Based Alternatives Program:

A program funded by state and federal dollars to provide services that assist individuals 18 and older to remain in their home. Clients must meet medical and income eligibility requirements. The program provides services based on the individuals needs such as case management, personal care, homemaking, respite, emergency response systems, or other equipment.

Home Health Services:

Nursing, personal care, or other services provided in the home by a licensed health professional, such as a registered nurse (RN) or certified nursing assistant (CNA). Services must be ordered by a physician and must be medically necessary to maintain or improve a health condition.

Instrumental Activities of Daily Living (IADL):

This term is often used by healthcare professionals to assess the need and/or type of care a person may require to perform tasks or activities, not necessarily done every day, but which are important to independent living. Examples include preparing meals, doing housework, doing laundry, using transportation, shopping, managing money, using the telephone, and doing home maintenance.

Long-Term Care Ombudsman:

A Long-Term Care Ombudsman has authority under Federal and State laws to advocate for and help protect the rights of residents, 60 and older, living in nursing homes, assisted living facilities, and adult foster care. An Ombudsman receives and investigates complaints from residents, family members, facility staff, or any concerned about a long-term care resident. These concerns may include quality of care, food, finances, visitors of choice, or resident rights.

LIS/Extra Help (Low-income assistance to pay for Medicare Prescription Part D drug costs):

Anyone who has Medicare can get Medicare prescription drug coverage. Some people with limited resources and income also may be able to get Extra Help to assist in paying for monthly premiums, annual deductibles, and prescription co-payments related to a Medicare prescription drug plan.

Medicare:

Medicare is health insurance for individuals 65 and older, people under 65 with certain disabilities, people of any age with end stage renal disease, permanent kidney disease requiring dialysis or kidney transplant. Different parts of Medicare cover specific

services. (For more information the “Medicare and You” book is available on line at: www.medicare.gov)

Medicare Part A (Hospital Insurance):

Medicare Part A helps cover inpatient care in hospitals, including critical access hospitals and skilled nursing facilities (not custodial or long-term care). It also helps cover hospice care and some home health care. You must meet certain conditions to get these benefits.

Cost: You may pay deductibles and co-pays for services.

Medicare Part B (Medical Insurance):

Medicare Part B helps cover your doctors’ services and outpatient care. It also covers some other medical services that Part A doesn’t cover, such as some of the services of physical and occupational therapists, and home health care. Part B helps pay for these covered services and supplies when they are medically necessary.

Cost: Monthly Medicare Part B premium, deductibles, and co-pays.

Medicare Part D (Prescription Drug Coverage):

Medicare Part D helps cover prescription drug costs. You must choose a plan to get this coverage.

Cost: You pay a monthly premium, deductibles, and co-pays. If you have limited income and resources, you may qualify to receive extra help for paying the premium.

Medicaid:

Health insurance that also covers community support services for certain groups of low-income individuals. The Medicaid program is different in every state, so be sure you get information about Utah Medicaid. The website for the Utah Medicaid program is:

<http://health.utah.gov/medicaid>. You can apply for Medicaid at any Utah Department of Workforce Services office or you may apply online at <https://jobs.utah.gov/mycase>. You can also call the Medicaid Information Line at 1-800-662-9651.

Medicaid Aging Waiver Program:

Individuals receive all of the standard Medicaid benefits as well as the additional benefits of the Aging Waiver. To be eligible for the Medicaid Aging Waiver, an individual must be age 65 or older, a resident of the State of Utah, be eligible for Medicaid, and meet medical eligibility. A case manager works to develop a care plan with the goal of assisting the individual to remain at home with services. The case manager assists with accessing community resources, authorizing use of Medicaid services, assuring quality of services provided, and assuring that the health and safety needs of the individual are met in a home setting. For further information contact your local Area Agency on Aging or the State Division of Aging at 1-801-538-3910.

New Choices Waiver:

This program helps eligible individuals move out of nursing facility settings and back in the community. To qualify, an individual must be 18 years of age, eligible for Medicaid, have resided in a nursing home for a minimum of 90 days or an assisted living for 6 months paying privately, and be medically eligible for long-term care services. Medicaid or Medicare must have paid for the nursing home stay 30 days immediately prior to discharge.

An assessment by a social worker and registered nurse is completed to determine the individual's care needs. A care plan is developed and services are arranged and monitored to meet the goal of helping the individual remain in a home setting with services.

Eligibility for this waiver is determined by the Utah Department of Health, Long-Term Care Bureau. For further information contact them at 801-538-6155 or 800-662-9651, or e-mail newchoiceswaiver@utah.gov. Go to www.health.utah.gov/ltc to learn more.

Personal Emergency Response System:

An electronic device that allows an individual to summon assistance in an emergency. The device is connected to a signal response center which is staffed 24 hours a day, 7 days a week by trained professionals responsible for dispatching assistance in the event of an emergency.

Private Pay:

Using your personal financial resources to pay an individual or agency for in-home services. A listing of agencies is available from the local phone book, senior center, or Area Agency on Aging. Training Module 8, Working Effectively with In-Home Service Providers, has more information and is available at www.ucare.utah.gov.

Respite Care Services:

Care, supervision, or companionship provided by an attendant, companion, homemaker, home health aide, etc. which is provided to relieve a caregiver or in the absence of a caregiver.

Senior Companion:

Senior Companions are volunteers 55 and older who want to share their experience and compassion with frail older adults to help them remain in their home. Whether giving families or caregivers

much needed time off, running errands, or simply being a friend, volunteers strengthen and preserve an individual's independence.

Senior Health Insurance Information Program (SHIP):

A free, confidential service that helps Medicare beneficiaries make informed decisions about Medicare and other health coverage. The Senior Health Insurance Information Program operates in every county in Utah. Contact your local Area Agency on Aging or the Division of Aging and Adult Services at 801-538-3910 or Toll Free at 800-541-7735 for more information.

Spenddown:

Spenddown is when you pay to receive a Medicaid card. You pay the amount that you are above the Medicaid income limit. You must meet all other conditions to qualify. Not all Medicaid programs allow you to spenddown.

Utah Caregiver Support Program:

Information, assistance, respite, supplemental services, and support groups for the following individuals:

- Caregivers of adults 60 years or older
- Caregivers 60 years of age who are caring for persons with mental retardation and related developmental disabilities
- Grandparents, 55 years or older who are relative caregivers of a child not more than 18 years of age

For information on services and activities in your area, contact your local Area Agency on Aging or the State Division of Aging at 801-538-3910.

Waiver and EPAS Coverage

	New Choices Waiver	Acquired Brain Injury Waiver	Physical Disabilities Waiver	Community Supports Waiver	Employment Related Personal Care Services (EPAS)	Medically Fragile Technology Dependent Children
Home Health – Licensed Health Professional	X	X	X	X	X	
Home Health – CNA	X	X	X	X		
Personal Attendant Service	X		X	X	X	
Companion Service	X	X		X		
Homemaker Service	X	X	X	X	X	
Chore Service	X	X		X		
Respite Care Service		X	X	X		
Fiscal Management Service	X		X	X	X	
Transportation		X		X	X	
Medical Equipment and Supplies	X	X		X	X	
Case Management	X	X			X	
Adult Day Care	X					
Individual Counseling	X			X		
Support Group						
Home Delivered Meals	X					
Hospice						

UCARE MODULE TOPICS

1. Providing Personal Care
2. Dementia and Memory Loss
3. A) Caring for Older Adults with Chronic Health Issues
3. B) Caring for Children with Special Health Care Needs
4. The Accessible Home
5. Taking Care of the Caregiver
6. Caring for those with Depression, Anxiety, Stress, or Mental Health Issues
7. Community Supports for Remaining at Home
8. Working Effectively with In-Home Service Providers
9. Keeping Your Home and the Person You Care for Safe
10. Eating Healthy for Life
11. Assistive Devices: Tools to Help You
12. Legal and Financial Matters: What You Need to Know

For more information, please visit: <http://www.ucare.utah.gov>

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For more information, please visit: <http://www.ucare.utah.gov>,
or email: ucare@utah.gov

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