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The National Consumer Voice for Quality Long Term Care

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Friends of Residents in Long Term Care is a nonprofit charitable organization committed to advancing quality of life in North Carolina’s long-term care. We advocate for changes in public policy, support families of long-term care residents, and help build public awareness in North Carolina about issues facing long-term care residents and their families.

Our Mission: To advance the quality of life in long-term care in North Carolina
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Introduction

Almost all of us will need some assistance with every-day tasks at some point in our lives. This type of assistance is referred to as “long-term services and supports” or “long-term care” - terms which we will use interchangeably in this document. If you are an older adult, you may need help due to the development of one or more chronic conditions, like arthritis, which make activities like bathing, dressing, and getting around more difficult. Or you may require assistance – regardless of your age -- because of a disability such as cerebral palsy or traumatic brain injury or because of severe and persistent mental illness.

There is a spectrum of long-term care services, from receiving limited assistance in your home to receiving around-the-clock care in a skilled nursing facility. The level of care you require may increase and decrease over time. However, all long-term care should be tailored to your individual needs and preferences.

The North Carolina system of long-term services and supports is complicated and confusing. Figuring out how to get quality services that fit your needs can be difficult. This Guide is designed to educate and empower you, the consumer, to advocate on your own behalf for the right kind of long-term care at the right time and with the right provider so you have independence, choice, dignity, and quality of life. This Guide will also be helpful to members of your family or others whom you may choose to assist you in this process.

After you have had an opportunity to explore long-term service options and decide what is right for you, one of the most important next steps you can take to insure that your choices are respected is to consider an Advance Directive. In an Advance Directive, you can communicate your wishes regarding your healthcare to someone you trust, and you can authorize that individual to carry out your wishes in the event you become incapacitated and are no longer able to make decisions for yourself. Advance Directives will be further described in Chapter 11.

But first, let’s find out more about long-term care.

Try to educate yourself about long-term care BEFORE you need it. This will allow you to make more informed decisions with less stress.
CHAPTER 1: What is Long-Term Care?

Long-term care, sometimes referred to as **long-term care services and supports**, refers to any assistance over a prolonged period to help address social, psychological, environmental, medical, or financial needs.

Long-term care often includes assistance with **activities of daily living** (ADLs). Activities of daily living are fundamental life tasks such as bathing, dressing, eating, toileting (e.g., getting to/from and on/off the toilet), and mobility (e.g., getting around or transferring from a bed to a chair/wheelchair). Long-term care can also include assistance with **instrumental activities of daily living** (IADLs), e.g., housekeeping, meal preparation/cleanup, shopping, accessing transportation, running errands, using the telephone/computer, and banking/managing money.

Long-term care should be person-directed or person-centered. **Person-centered care** focuses on your strengths and preferences and puts you in charge of determining the direction of your life. You should have the opportunity to express preferences and make decisions in meaningful ways at every level of daily life.¹ When care is person-centered, you are the one directing or guiding the services you receive, including when you receive them and how you receive them instead of having decisions made by professionals or family members. More recently, the concept of person-directed care has become the heart of “culture change,” a movement to provide services to older adults and persons with disabilities in a way that values choice, dignity, respect, self-determination, and purposeful living.²

Person-centered care is related to a Medicaid concept called **self-direction** or **self-determination**. If you are eligible for Medicaid Waiver services, (see Chapter 10) you can choose to be part of the self-directed CAP-Choice/Independence Plus waiver. Under this waiver, you have the authority to hire, fire, train, schedule, and supervise your attendants. You also have the responsibility to find replacement attendants when one takes time off, and you are responsible for wages and payroll taxes with the assistance of a fiscal intermediary or public authority. Appendix 3 offers a worksheet to help you determine if self-direction is right for you.

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**The goal of long-term care is to help you live as independently as possible, with the greatest quality of life.**

¹ [http://www.pioncernetwork.net/CultureChange/](http://www.pioncernetwork.net/CultureChange/)
CHAPTER 2: Receiving Care in your Home or Community

If you ask people where they want to receive care and services, most will say “in my own home.” The increasing availability of **Home and Community-Based Services** (HCBS) has enabled many consumers to receive long-term care while remaining in their own homes and continuing to enjoy their independence.

Broadly stated, HCBS are designed to achieve the following objectives:

1. ensure your safety
2. assist you with activities of daily living/instrumental activities of daily living
3. teach new skills or provide therapies to restore or maintain your abilities
4. help you maintain good physical and mental health
5. modify your home and/or your vehicle to make them accessible
6. provide you with the supplies/equipment you need to live in the community
7. train you, your family, and your caregivers
8. provide transportation to appointments

For many people it is less expensive to receive care in their home than to move into a facility, such as a nursing home or assisted living center. Home and Community Based Services may be paid for by the Medicaid State Plan or Medicaid Waivers, by Medicare, Long-Term Care Insurance, VA benefits, or purchased privately from your own resources. These payment options are described in Chapter 10.

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| Therapies: physical, occupational, respiratory, speech/language | Physical therapy: assessment, treatment and training to maintain or improve functioning such as strength, muscle tone and mobility.  
Occupational therapy: Assessment, treatment and training to increase a persons’ ability to perform self-care and other activities in order to maximize independence and quality of life. May include adaptation of tasks or equipment.  
Respiratory therapy: Assessment, treatment and management of breathing disorders.  
Speech/language therapy: Assessment and treatment for speech and language communication disorders and swallowing problems. |
| Transition Services              | A Medicaid benefit that covers one-time expenses not to exceed $2500 per person to set up a home in the community after transitioning from an institutional setting |
| Transportation Services          | Transportation for appointments and errands                                  |
| Vehicle Adaptations              | Modifications to a vehicle that allow a person to use it to access the community and remain independent |
| Vocational – Long-Term Support   | Assistance in maintaining a job when Supported Employment services are no longer needed/available |
CHAPTER 3: Receiving Care in a Facility

Sometimes you will want or need an option other than remaining in your current home. For example, your current home may have become too difficult to maintain, may not be accessible, or may be too expensive. This chapter describes a number of housing options that provide long-term care services.

**Supportive housing** is rental housing with services for low-income persons with disabilities and older adults. Services may include nutrition services, health-related services, mental health services, services for non-medical counseling, meals, transportation, assistance with activities of daily living, assistance with chores, safety, socializing, help with medications, and case management. The most common forms of supportive housing are HUD Section 202 Supportive Housing for the Elderly and Section 811 Supportive Housing for Persons with Disabilities.

There are also some supported living programs for persons with developmental disabilities, mental illness, or brain injuries. In these programs a very small number of persons share an apartment or home and are supported by a range of services, depending on their disability. Services may include up to 24-hour attendant care.

**Mental Health Group Homes** are licensed under General Statute 122-C to provide care and services to adults with developmental disabilities, traumatic brain injury, mental illness, or substance abuse disorders.

- **Supervised Living Facilities** provide 24-hour residential services to 2 or more adults in a home environment where the primary purpose of services is care, habilitation, and treatment.

- **Intermediate Care Facilities for Individuals with Intellectual/Developmental Disabilities (ICF/IID)** provide 24-hour residential services to 2 or more adults with significant developmental disabilities and habilitation needs requiring additional staff support. In addition to meeting licensure requirements, ICF/IID facilities must also follow Medicaid regulations.

Local Management Entities - Managed Care Organizations - assist persons with admission to these facilities and monitor the provision of services. Contact information is available at [www.ncdhhs.gov/mhddsas/lmedirectory.htm](http://www.ncdhhs.gov/mhddsas/lmedirectory.htm)

For a complete listing of all licensed facilities for Mental Health, Developmental Disabilities, and Substance Abuse Services organized by county, go to [www.ncdhhs.gov/dhsr](http://www.ncdhhs.gov/dhsr).
Assisted Living provides group housing for 2 or more unrelated adults along with services including meals, housekeeping, and personal care services provided directly or through written agreement with a licensed home care agency. Assisted living facilities provide a different level of care than nursing homes. Assisted living facilities do not provide ongoing skilled nursing care.

There are three types of assisted living facilities:

- **Adult Care Homes** are licensed under General Statute 131D to serve 7 or more adults who may require 24-hour supervision and/or assistance with personal care needs. Individuals live in a group residence where there is a common dining area and common areas for social and recreational activities. Staff provide personal care and supervision and health care services. Other services include three meals per day, laundry and housekeeping services, and a program of individual and group activities. Some facilities provide special units for persons with Alzheimer’s Disease and other related disorders. Such units are usually in a secure part of the facility and have activity programs specifically designed for persons with dementia. As of March 1, 2013 all licensed adult care homes must assure that any individual admitted has a pre-admission screening for serious mental illness or mental retardation to determine if adult care home placement is appropriate. The screening will use the PASRR Medicaid Level I screening form, completed by an independent healthcare professional, and, if necessary, a Level II face-to face evaluation.

- **Family Care Homes** are licensed under General Statute 131D to serve 2 to 6 adults who may require 24-hour supervision and/or assistance with personal care needs. Individuals live in the home of an unrelated individual. Staff provide the same basic services as those provided in adult care homes.

- **Multi-Unit Assisted Housing with Services** are unlicensed facilities that house adults who do not require 24-hour supervision and/or assistance with personal care needs. Individuals typically live in their own apartment within a multi-unit complex with protective oversight. If personal care and nursing services are needed, they are arranged by housing management and provided by a licensed home care or hospice agency through an individualized written care plan.

Local Departments of Social Services (DSS) assist with admission to assisted living facilities. Necessary forms for admission to assisted living and additional information are available at [www.ncdhhs.gov/dss/local](http://www.ncdhhs.gov/dss/local)

For a list of assisted living facilities in NC, go to [www.ncdhhs.gov/dhsr](http://www.ncdhhs.gov/dhsr)
You can search for an adult care home’s quality rating on [http://www.ncdhhs.gov/dhsr/acls/star/search.asp](http://www.ncdhhs.gov/dhsr/acls/star/search.asp)
**Nursing Homes**, also called **Skilled Nursing Facilities**, are licensed under General Statute 131E. Nursing homes provide services and supports to people who need ongoing nursing care provided by a skilled nursing professional. They provide a standard set of core services that include room and board, personal care, nursing services, dietary services, social services, activities, and housekeeping. Nursing homes must also provide or arrange for therapy, such as physical therapy, occupational therapy or speech/language therapy; dental care; podiatry services; optometry services and transportation to medical appointments. Some nursing homes provide skilled nursing care and rehabilitation therapy after an injury or hospital stay. Others may have a special unit for residents with Alzheimer’s disease or another form of dementia. These units may be referred to as “memory care,” dementia,” “Alzheimer's” or “behavioral” units.

Individuals with mental illness are not eligible for nursing home care solely on the basis of their mental illness. They must also need the type of care provided by a nursing home – such as assistance with activities of daily living or care for a medical condition. A screening (PASRR – Pre-Admission Screening and Resident Review) is done to determine, among other things, if a person with a mental illness needs nursing home care. The purpose of the screening is to make sure that someone is not admitted to or allowed to continue living in a nursing home when they could receive services and supports in the community.

Admission to a nursing home requires completion of an FL-2 medical form by your doctor confirming that you need nursing facility level of care. The Department of Social Services in your county can provide you with this form and assistance in locating a placement: [www.ncdhhs.gov/dss/local](http://www.ncdhhs.gov/dss/local)

For a complete list of nursing homes in your area go to [www.ncdhhs.gov/dhsg](http://www.ncdhhs.gov/dhsg) and click on “Licensed Facilities” and then Nursing Facilities.

After you have learned where the nursing homes near you are located, go to [www.medicare.gov/NHcompare](http://www.medicare.gov/NHcompare) to learn how the quality of each facility is rated using a five-star rating system. Health inspection results, quality measures, and staffing ratios are components of the rating system.
**Continuing Care Retirement Communities** (CCRCs) are housing communities that offer several levels of care in one location. Where people live depends on the level of care they need. In the same community, there may be individual homes or apartments for residents who still live on their own, an assisted living facility for people who need some help with daily care, and a nursing home for those who require higher levels of care. Residents move from one level of care to another based on their needs but still stay within the CCRC campus or location.

CCRCs generally charge a large payment before a person moves in (called an entry or entrance fee) and then charge monthly fees. The fees vary according to whether the resident owns or rents the living space, the size and location of the residence, the amenities chosen, whether the living space is for one or two individuals, the type of service contract chosen, and the current risk for needing intensive, long-term care.

CCRCs in North Carolina are regulated by the Department of Insurance. Any questions about CCRCs may be directed to the Dept. of Insurance at (919) 807-6612.

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CHAPTER 4: Moving out of a Nursing Home

What is “nursing home transition”? 
Nursing home transition\(^3\) refers to the process by which individuals living in a nursing home are assisted in moving to a less restrictive community setting. The right to choose where you live and where you receive care and assistance is guaranteed under the Americans with Disabilities Act and supported by the U.S. Supreme Court’s Olmstead Decision.

A federal grant program, called “Money Follows the Person” provides funding to move residents from institutions to the community.

Beginning on October 1, 2010, the Centers for Medicare and Medicaid Services put in place a program to help residents in Nursing Homes look at the possibility of transition. Residents should be asked if they are interested in transitioning out of a nursing home, and if they are, a referral is made to the Local Contact Agency(s) (LCA). This is an entity responsible for contacting residents and discussing transition options. The LCA is responsible for providing accurate and unbiased information to the person living in the facility about resources available in the community to support a successful and sustainable transition.

The Local Contact Agency is there to support, not to replace, the facility social worker who has the lead role in formulating and implementing a transition plan.

Whom do you contact if you want to move out of your nursing home?
You can start by telling the social worker that you want to move back to the community. You can also tell other nursing home staff at the time of your annual assessment, called the Minimum Data Set (MDS). The MDS contains a section of questions about moving out of the nursing home. If you indicate that you want to transition back into the community, nursing home staff makes a referral for you to the Local Contact Agency.

What does the Local Contact Agency do?

Upon receiving a referral, someone from the LCA will schedule a visit with you. During the face-to-face visit, the LCA contact person will get a bit of history from you about your life prior to moving into the nursing home, the kinds of services and supports you receive, family members and others who are part of your informal support network, other kinds of resources you have and where you think you might live in the community. If you would like, family members, the ombudsman and others may attend this meeting with you to add their comments and to provide additional information.

At the conclusion of the meeting, the LCA contact person will convene a Community Transition Resource Team. The members of this team will depend on your individual needs but will probably include representatives from the following groups:

- County Department of Social Service
- Long Term Care Ombudsmen
- Family Caregiver Support Specialist
- NC Division of MH/DD/SAS Service Provider
- Housing Specialist
- Community Care Network of North Carolina
- Money Follows the Person Transition Staff
- Center for Independent Living

The Transition Resource Team will review the information that you shared with the LCA contact person and then determine what community resources are available to help you make a successful and sustainable transition. These resources will be discussed with you and others of your choosing, e.g. family members, nursing home social worker.

What should a transition plan include?

Once you know what your options are, you and the nursing home social worker should work collaboratively to develop your transition plan. The plan needs to cover all aspects of your life. Here are just some of the areas that should be included.

**Housing.** The goal is to find affordable, accessible housing in the community. This can be extremely difficult because the demand is great. Prepare to have your name placed on a long waiting list. You will also need to make sure you have or that the transition program helps you obtain household goods, furniture and other necessities to set up your new home and works with you to ensure the utilities are on when you move in. Make sure the location is close to the things you need and value.
**Personal Assistance.** You will need to think about who will assist you with activities such as bathing, dressing, positioning, shopping for groceries and other items you need, laundry and more. Will you hire your own attendant/aide or use one provided through an agency? Will your attendant/aide help you with meal preparation or do you want home-delivered meals? As with housing, there can be very long waiting lists for care/services provided through a Medicaid Waiver or other programs. You want this assistance in place so you can begin receiving care/services as soon as you move out of the nursing home.

**Transportation.** Accessible and affordable transportation is critical when you live in the community. Research what options are available, costs and any limits on where you can go. Often transportation providers can only operate in one county.

**Health Care.** Do you already have a doctor in the community or do you need to find one? If going to a doctor’s office is difficult, you may need to see if you can find a doctor that comes to your home. An increasing number of physicians now make house calls.

If there are other health care professionals who provide care to you in your nursing home, such as podiatrists, dentists or psychiatrists, you will need to arrange to see them in their offices or find new providers. Any therapy you require or nursing care that must be given by a licensed nurse should also be arranged in advance.

Make sure you have a plan in place for getting your medications once you leave the nursing home. Consider how your medications will be paid for and whether you need to apply for programs to help cover co-pays. In addition, think about how you will receive your medications. You may want to research whether there is a pharmacy that will deliver and, if so, make the necessary arrangements. *Don’t forget to take your remaining medications with you from the nursing home when you leave!*

**Home modification/assistive technology/durable medical equipment.**
What do you need in order to live comfortably in your home and to function as independently as possible in all aspects of your life? See the definitions (in Chapter 2) of home modification, assistive technology, and durable medical equipment to get an idea of what might be helpful to you.

**Adult day services/programs.** See the range of services listed in Chapter 2. Your transition coordinator can assist you in connecting to these services.
**Finances.** There are also financial matters that need to be addressed in order to move back into the community. Many individuals will have to take care of the following:

- Applying for Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI). If you have SSI, notify the Social Security Administration so your SSI will increase after you leave the nursing home.

- Applying for private living Medicaid. While you are in the nursing home, you have what is called “long term care” Medicaid. When you move out of the facility, however, your Medicaid doesn’t automatically transfer to the community.

**Beware — eligibility criteria for long-term care Medicaid and private living Medicaid are different, so you may not be eligible for Medicaid benefits if you leave the nursing home.**

**Roles of Family and Friends.** Mobilize your “circle of support” or form one to support you once you are back in the community. Connecting with family, friends, neighbors, or others you know can reduce the sense of isolation you may experience and make the adjustment process easier.

**Community Connections.** Being involved in the community is important to many people. This could include participating in a faith community, taking part in recreational activities, going to a senior center, volunteering, or being a member of a club or service organization. It is a good idea to think about how you would like to connect with the community prior to moving out and even become active beforehand.

You, the nursing home social worker and anyone else you would like to join you will develop your plan. Participate actively in creating your transition plan! Take the lead if possible. Once the plan is completed, create a master checklist and schedule with a section indicating who is responsible for each task and by what date.

**How do I implement the plan?**

During this part of the nursing home transition process, you, the nursing home social worker, and anyone else you have asked to join you will work to make the transition happen.

Get as involved in carrying out the transition activities as you can by making the calls, requesting information, asking for applications, conducting research, submitting
applications, etc. The more responsibility you take on, the more practice you will have in handling the tasks and activities that you will need to do for yourself after the move.

Many people are able to transition out of the nursing home in a short time. The services and supports they need are available, and they return to homes or apartments they had before, find a new apartment, move in with family or enter an assisted living facility.

In some situations, however, you may have to wait for services or housing, particularly if you need subsidized, accessible housing. Because there are often waiting lists, it may take a while to find housing that is both subsidized and accessible. Some waiting lists are quite long. Try to put that time to good use. Start connecting with the community, perhaps by taking part in an activity you like. You can also learn or brush up on independent living skills through your local Center on Independent Living. If you will be hiring your own attendant, you can learn more about hiring and supervising attendants through attendant care training manuals.

If you qualify, money may be available through the Money Follows the Person grant program to pay for the security deposit, first month’s rent, setting up utilities, and other items such as furniture.

Your Money Follows the Person transition coordinator will help if necessary with obtaining furniture, moving your possessions into your new home, making sure you have food and necessary medications, and other aspects of the move.

Before you move out of the nursing home, there should be a discharge planning meeting. Use that meeting as an opportunity to make sure everything is in place.

The Money Follows the Person transition coordinator may work with you for a year after you leave the nursing home. His or her role is to provide you with follow-up support and to help make sure your needs are being met. At some point, the transition coordinator will be replaced by a care manager.
CHAPTER 5: Additional Housing Options

The options in this chapter typically do not provide long-term care services on-site, but, just as you can arrange for services in your own home, you can often arrange for home and community-based services to be provided in the settings described below.

**Subsidized housing** is housing for people with a low-income. Federal subsidized housing is provided through the Department of Housing and Urban Development (HUD).

- *Public housing* - usually apartments that are available at a rate less than what is normally charged in the community. Apartments are often part of public housing projects. For more information, call (202) 708-1112, TTY (202) 798-1455 or go to: [http://portal.hud.gov/portal/page/portal/HUD/topics/rental_assistance/phprog](http://portal.hud.gov/portal/page/portal/HUD/topics/rental_assistance/phprog).

You can apply for public housing at a public housing agency. To find the public housing agency near you, go to [http://www.hud.gov/offices/pih/pha/contacts/index.cfm](http://www.hud.gov/offices/pih/pha/contacts/index.cfm) or call the Public and Indian Housing (PIH) Customer Service Center at (800) 955-2232 and request information.

- *Housing Choice Vouchers* - issued to individuals or families and can be used to pay for any housing unit where the owner agrees to rent under the Housing Choice Voucher Program. This program is commonly referred to as “Section 8.” The voucher will cover all or part of the rent. The application process is the same as it is with public housing.

- *Privately owned subsidized housing* - HUD helps apartment owners offer reduced rents. You can find additional information about this option by going to: [http://www.hud.gov/apps/section8/index.cfm](http://www.hud.gov/apps/section8/index.cfm) or calling the PIH Customer Service Center listed above.

**If you are considering living in any type of subsidized housing, apply as soon as you possibly can. Be prepared to be put on a long waiting list.**

**Senior housing** is housing in a private apartment or house in a community of adults who are age 55 or older or sometimes 62+. Senior housing typically does not provide services on-site, but seniors can hire their own services or get their health care services outside of their home environment. Some communities provide a lot of recreational and social activities, while others offer few amenities. See subsidized housing above for information about low-income senior housing.
CHAPTER 6: Your Housing Rights

Knowing your rights as a tenant is very important. Many of your rights come from the Fair Housing Act, which gives persons with disabilities significant protections. Since the federal law defines a disability broadly, many older adults qualify as persons with disabilities.

The Fair Housing Act applies to anywhere that someone considers “home.” It does not apply to a hotel or hospital, but it does apply to nursing homes, assisted living facilities, senior communities and other places where people live.

Under the law, a landlord cannot take any of the following actions based on disability:

- Refuse to rent or sell housing
- Refuse to negotiate for housing
- Make housing unavailable
- Deny a dwelling
- Set different terms, conditions or privileges for sale or rental of a dwelling
- Provide different housing services or facilities
- Falsely deny that housing is available for inspection, sale or rental
- For profit, persuade owners to sell or rent (blockbusting)
- Deny anyone access to or membership in a facility or service (such as a multiple listing service) related to the sale or rental of housing.

In addition, you have the right to:

- Make reasonable modifications to your dwelling or common use areas, at your expense, if it is necessary for you use the housing. (Where reasonable, the landlord may permit changes only if you agree to restore the property to its original condition when you move.)
- Make reasonable accommodations in rules, policies, practices or services if necessary to use the housing.4

4 http://www.hud.gov/offices/fheo/FHLaws/yourrights.cfm
CHAPTER 7: Overcoming Barriers to Obtaining Housing

Unfortunately, you may face some barriers in obtaining housing. Here are some common barriers and what you can do to overcome them.

**Barrier #1:** Shortage of housing. If there are far too few housing units to meet the demand, you may be put on a long waiting list.

**Solution:** Apply for housing as soon as possible, even if you’re not sure you will definitely need it. Apply for all types of housing for which you qualify. For example, if you are applying for Section 8 and HUD subsidized housing, take the first one that comes up. You can always switch to the other one as it becomes available.

Join or support an organization that is advocating for more affordable, accessible housing. While this won’t help you immediately, it could make a difference in the future.

**Barrier #2:** Lack of knowledge about the existence of affordable, accessible housing.

**Solution:** Contact your closest Center for Independent Living, Area Agency on Aging or local Community Resource Connections for Aging and Disabilities (CRC).

**Barrier #3:** Housing claiming to be accessible is not accessible to you. For example, you are a wheelchair user, and there is no roll-in shower in an apartment you are considering.

**Solution:** Request a “reasonable modification” of the current shower in the apartment (although you will most likely have to pay for it yourself unless you are in federally subsidized housing). It is best to make such a request in writing. See Appendix 3 for a sample letter that you could use.

**Barrier #4:** Your request for a reasonable modification or accommodation is denied, or you have been trying to rent or buy an apartment or home and feel you have been discriminated against.

**Solution:** File a complaint with the Office of Fair Housing & Equal Opportunity.

**Office of Fair Housing & Equal Opportunity**
Department of Housing and Urban Development (HUD)
451 Seventh Street SW Washington, DC 20410-2000
1 (800) 669-9777

File a complaint online at [http://www.hud.gov/offices/fheo/online-complaint.cfm](http://www.hud.gov/offices/fheo/online-complaint.cfm). To assist persons with disabilities in filing the complaint, HUD will provide a toll-free TTY phone for the hearing impaired (1-800-927-9275), interpreters, tapes and Braille materials and assistance in reading and completing forms.
CHAPTER 8: Hospice

The goal of hospice is to improve a person’s last days and to allow him or her to die pain-free and with dignity. Hospice is designed to care not just for a person’s physical needs but for his or her emotional, social and spiritual needs as well. Hospice care can be provided in any setting – in your own home, a group home or assisted living, or in a nursing home or ICF/MR. There are also an increasing number of free-standing hospice facilities.

Who qualifies for hospice services?
To qualify for hospice care, your physician must certify that you are terminally ill. An individual is considered terminally ill if death is expected within six months or less. This does not mean that care will only be provided for six months. Hospice can be provided as long as the person’s physician and hospice team certify the condition remains life-limiting.

What services does hospice provide?
A wide range of services is available through hospice:

- Physician services
- Nursing care
- Physical therapy, occupational therapy and speech/language therapy services
- Medical social services
- Home health aide services
- Homemaker services
- Medical supplies, including drugs and medical appliances
- Counseling, including dietary counseling, counseling about care of the terminally ill patient and bereavement counseling for family that continues for at least 13 months following the death of the individual
- Short-term inpatient care for respite care, pain control and symptom management

To find a hospice provider, go to [www.hospicedirectory.org](http://www.hospicedirectory.org)
Or call the Hospice Directory at (800) 854-3402.
CHAPTER 9: Finding Information and Determining Needs

How can I get more information about long-term care?

You can obtain information about long-term care from a number of places:

**Eldercare Locator.** This is a free national service, providing written information about long-term support options in general and connecting you to resources in your own community. To contact the Eldercare Locator, call (800) 677-1116 or go to: [www.eldercare.gov](http://www.eldercare.gov).

**Area Agencies on Aging (AAA).** An Area Agency on Aging is a non-profit organization that coordinates a range of services to assist older adults in a particular community or region. They are located in communities all across North Carolina. Many AAAs also serve younger persons with disabilities and may have some programs that are available to anyone age 18 or older. The AAA can connect you with the right information and available services for your particular situation. You can find the Area Agency closest to you by going to: [http://www.aoa.gov/AoAroot/AoA_Programs/OAA/How_To_Find/Agencies/find_agencies.aspx](http://www.aoa.gov/AoAroot/AoA_Programs/OAA/How_To_Find/Agencies/find_agencies.aspx)

or call the Eldercare Locator number: (800) 677-1116

**Centers for Independent Living (CIL).** CILs are grassroots, advocacy-driven organizations run by and for people with disabilities. CILs help promote the independence and productivity of persons with disabilities, and they often have expertise in assisting people with disabilities arrange for housing and supports in the community. One of the CIL’s core services is to provide disability-specific information and referral services. To locate a CIL near you, go to: [http://www.virtualcil.net/cils/](http://www.virtualcil.net/cils/) or call (877) 525-3400.

**Community Resource Connections for Aging and Disabilites (CRC).** This is the North Carolina version of the national Aging and Disability Resource Centers. The CRC is a network of community-based service providers that offer a wide array of services including information, assistance, options counseling and referral to both the aging and adult disability populations in order to streamline access to long term services and supports CRCs are not yet available on a statewide basis. To determine if your community has a CRC, go to: [http://www.adrc-tae.org/tiki-index.php?page=ADRCLocator](http://www.adrc-tae.org/tiki-index.php?page=ADRCLocator) or call (800) 677-1116.

**Family and friends.** The people you know may be able to tell you how to find information and resources about long term care, services and supports.
Department of Veterans Affairs (VA). The VA offers a range of services to veterans who need long-term care. For information and resources, contact the social work department of any VA Medical Facility; call 1 (877) 222-8387, or visit www.va.gov (Click on “Veteran Services”).

How do I figure out what care, services, and supports I need?
In the world of long-term care, assessment generally means the process used to determine in what areas you do or don’t need assistance and whether you are eligible for certain programs that provide services and supports. Different assessments may be required to obtain various services and supports. Assessments are conducted by a number of professionals including:

- Care managers located through the AAA or a local aging program.
- Care coordinators or other professionals at the Local Management Entity – Managed Care Organization - (for persons with mental illness, developmental disabilities, or substance abuse disorders)
- Care managers through social service organizations in the community (e.g. Catholic Social Services, Family Services Association, Jewish Family and Children Services)
- Private geriatric care managers - “Private” means you must pay out of your own pocket, although some long-term care insurance policies may cover this service. To find out more about private care managers, visit www.caremanager.org.

NOTE: If you would like financial assistance from the state or federal government for services, it is best to seek an assessment from your AAA or LME-MCO.

If you can, participate actively in your own assessment. The more information you provide, the more thorough the assessment. You may find it helpful to look at some assessment tools to give you an idea of the type of information that is collected. Several tools are listed in Appendix 1 under “Assessment Tools.”

Remember, long-term care should be tailored to meet your individual needs. You have the right to express your preferences and to choose the course of your care.
CHAPTER 10: Costs and Payment

What do long-term services and supports cost?
The question of cost is very important because in many instances your options are
determined by how much you can pay. To give you some idea of cost, below are some
average North Carolina costs in 2010 for home care services, adult day services,
assisted living and nursing home care.\(^5\) These are only averages. Costs may be higher
in some parts of the state especially in Charlotte or in the Raleigh/Durham area.

NOTE: For individuals who qualify for public funding such as Medicaid, rates are
lower and are established by the State Legislature.

Home care
Home health aide (from licensed agencies)................................. $18 per hour
Homemaker/companion services (from an agency) ......................$16 per hour
Attendant (national figures).......................................................... $8.91 – 11.99\(^6\) per hour
Note: This is the amount you pay the agency. It is not the amount the home health aide
or homemaker/companion receives.

Adult day services................................................................. $47 per day

Assisted living facilities........................................................... $3,397 per month
This is the monthly average base rate cost, which includes room and board, at least two
meals per day, housekeeping, and assistance with activities of daily living.

Supervised living facilities will cost at least the monthly average base cost of an
assisted living facility plus the cost of habilitation/rehabilitation services which will vary
with individual consumer needs.

Nursing homes
Private room................................................................. $204 per day; $74,460 per year
Semi-private room.............................................................. $182 per day; $66,430 per year

National Averages for Alzheimer’s units:
Private room, Alzheimer’s Unit ........................................... $228 per day; $83,220 per year
Semi-private room, Alzheimer’s Unit .................................... $206 per day; $75,190 per year

\(^6\) \url{http://www.payscale.com/research/US/Job=Personal_Care_Attendant_(PCA)/Hourly_Rate}
How do I pay for long-term care services?

There are a variety of ways to pay for long-term services and supports. Some payment options require you to meet certain physical and/or financial qualifications. A good resource is the Senior Health Insurance Information Program (SHIIP). SHIIP is a free counseling program within the NC Department of Insurance. Trained volunteers provide information about Medicare, Medicare supplements, Medicare Advantage, Medicare Part D and long-term care insurance. Counselors also help individuals recognize Medicare billing errors and possible fraud through the NC Senior Medicare Patrol Program. Contact the SHIIP Program Monday – Friday from 8:00 am – 5:00 pm at 800-443-9354 or 919-807-6900 or visit their website at http://www.ncdoi.com/SHIIP/Default.aspx.

Medicare

Medicare is a federally-funded program that provides health insurance for most people age 65 years and older, people under age 65 years with certain disabilities, and people of all ages with end-stage renal failure. Since Medicare is a federal program, the eligibility guidelines and services are the same all over the country. **You must enroll in Medicare when you are first eligible or you may have to pay a penalty fee for the entire time you receive benefits.**

Medicare coverage:

- **Medicare Hospital Insurance (Part A)** provides basic coverage for hospital stays and limited coverage for post hospital rehab, hospice, and home health care.
- **Medicare Medical Insurance (Part B)** pays most basic doctor and laboratory costs, and some outpatient medical services including medical equipment and supplies, physical therapy, and some home health care.
- **Medicare Part C, known as Medicare Advantage**, is an option in which private insurance companies receive money from Medicare to provide coverage. Medicare Advantage covers everything included in original Medicare Part A and Part B, except hospice care. Different companies can have different out-of-pocket costs, different ways of obtaining services, and different additional benefits.
- **Medicare Prescription Drug Coverage (Part D)** pays some of the costs of prescription medications.
Medicare will not pay for personal care services if that is all you need. You must also require skilled nursing care and/or therapies to qualify for coverage.

Medicare will completely cover the cost of your skilled nursing facility stay for the first 20 days if you need skilled services throughout that period. From days 21-100, Medicare will pay a portion of the cost of your care if you continue to require skilled services. You must pay part of the cost (called the “co-pay”) of your stay. Medicare does not pay at all after 100 days. **Medicare covers very little nursing home care.**

Medicare coverage ends when you no longer need skilled nursing care or therapy. Often a nursing home decides that you don’t qualify any longer and will notify you that it is stopping services. **The decision to discharge someone is frequently based on the incorrect belief that a person does not qualify for Medicare if he or she is no longer making improvement. Don’t fall for this.** You have the right to appeal the nursing home’s decision. Information about the appeal process can be found in Chapter 15.

**Hospice care** is covered if (1) you are eligible for Medicare Part A (hospital insurance); (2) your physician certifies that you are terminally ill (death is likely within six months or less); (3) you sign a statement choosing hospice care instead of routine Medicare-covered benefits AND (4) you receive care from a Medicare-approved hospice program.

**Beware** – If you are receiving hospice care in a nursing home, Medicare does not pay for room and board in the nursing home. This means that you will have to pay privately for that portion of your nursing home stay unless you are on Medicaid or have long-term care insurance or other insurance policy that includes hospice.

**Medigap.** Medigap is private supplemental insurance that pays for some things that Medicare won’t cover, such as deductibles and co-insurance. Medigap may also take care of the unpaid portion of the cost of nursing home care during days 21 – 100 if you still require that level of care.

Apply for Medicare online at [www.medicare.gov](http://www.medicare.gov). You may also contact a volunteer with your local Senior Health Insurance Information Program (SHIIP) to help you apply - [www.ncdoi.com/shiip/](http://www.ncdoi.com/shiip/).
Medicaid
Medicaid is a health insurance program financed and run jointly by the federal and state government for people who have limited income and resources (often called “assets”) and who meet certain eligibility criteria such as being age 65 or older, blind, or disabled.

Services covered by Medicaid include

- Ambulance Services
- Durable Medical Equipment
- Family Planning
- Early Periodic Diagnosis Screening and Treatment (EPSDT)
- Clinics
- Home Health
- Hospital Services
- Midwife and Nurse Practitioner
- Nursing Facility
- Other Lab and X-ray
- Physician
- Psychiatric Residential Treatment Facilities (PRTFS)

In North Carolina, Medicaid may also cover

- Case Management
- Adult Dental
- Hospice
- Mental Health
- Personal Care
- Prescription Drugs
- Physical Therapy, Occupational Therapy, Speech Therapy
- Transportation

Note – Qualifying for Medicaid does not mean that you will automatically qualify for every Medicaid service.

You can apply for Medicaid at your local Department of Social Services and learn more about NC Medicaid and services at the Division of Medical Assistance website at [www.ncdhhs.gov/dma/medicaid](http://www.ncdhhs.gov/dma/medicaid).
The Health Care Reform Act that became law in March 2010 has several provisions that will help make home and community-based services paid for by Medicaid more readily available. To learn more about these provisions, go to www.theconsumervoice.org (click on “Government Policy,” then “Health Care Reform”).

Medicaid Waivers
Federal law requires Medicaid to pay for long-term care services only when they are delivered in a hospital, nursing facility, or Intermediate Care Facility for Individuals with Intellectual Disabilities. However, states can receive a “waiver” of that requirement in order to provide long-term services and supports in the home and community. Under the waiver, states can provide a wide range of services such as homemaker, respite, home-delivered meals and care management that traditional Medicaid does not cover.

A person must meet two requirements to qualify for Medicaid Waiver services:

1) **Financial requirement.** The financial eligibility requirements for Medicaid Waivers are different from the requirements for traditional Medicaid. Individuals who would not financially qualify for traditional Medicaid may be eligible for waiver services. In other words, even if you have too many assets to qualify for traditional Medicaid, you might qualify for services under a Medicaid waiver.

2) **Level of care requirement.** An individual must need nursing home level of care or ICF/IID level of care.

North Carolina has the following waiver programs. *See Appendix 2 for more information about the services offered under each waiver.*

Community Alternatives Program for Disabled Adults (CAP-DA)
This program is for persons with chronic health problems or acquired disabilities who, without these services/supports, would have to live in a nursing facility. The services/supports must be delivered in the consumer’s own home.

**CAP/Choice**
CAP/Choice is an alternative to the CAP/DA program. The CAP/Choice program is for those who need nursing facility level of care but wish to remain at home and have increased control over their services/supports – such as selecting their own workers, tailoring their plan of care, directing their services, and paying their care providers. Again, the services/supports must be delivered in the consumer’s own home.

**NC Innovations**
This program is for individuals with intellectual and other developmental disabilities who
are at risk of placement in an intermediate care facility for individuals with intellectual/developmental disabilities (ICF/IID). This program provides an array of community-based services and supports to promote choice, control, and community membership. Unlike the first two waivers, individuals who qualify for this waiver can either live in their own home or in a small community supervised living arrangement. This waiver is intended for persons with significant service needs.

**Other payment methods**

**State/County Special Assistance.** This benefit is available to low-income individuals in group care facilities other than nursing facilities and ICF/IID facilities. It augments Social Security or SSI benefits to pay for room and board. Contact the Department of Social Services in your home county to apply for this benefit.

**State/County Special Assistance – In-Home Program.** There are a limited number of “slots” in 91 counties for low-income individuals who qualify for Assisted Living but want to remain at home and need financial assistance with rent, food, other basic expenses.

**Older Americans Act.** The Older Americans Act (OAA) is a federal law authorizing a wide range of services and programs for older adults and their families. The OAA provides funding for a number of home and community based services through state and local agencies, such as the State Unit on Aging and the Area Agencies on Aging. While there are no specific financial eligibility criteria for Older Americans Act services, they are generally targeted to low-income, frail seniors over age 60 and minority elders and seniors living in rural areas.⁷

**Veterans Affairs (VA).** Federal law requires the Department of Veterans Affairs to provide long-term care to veterans who meet established disability criteria or to those who need care because of service-connected disabilities. Low-income veterans may qualify for the Housebound benefit for care at home or the Aid and Attendance benefit for care either at home, in an assisted living facility, or in a nursing home. In addition, the VA provides nursing home services to veterans through VA-owned and operated Community Living Centers (CLC) and the contract community nursing home program. Each program has admission and eligibility criteria specific to the program and the amount paid varies. There are also state-owned and operated veterans’ homes.

⁷ [http://www.longtermcare.gov/LTC/Main_Site/Paying_LTC/Public_Programs/Public_Programs.aspx](http://www.longtermcare.gov/LTC/Main_Site/Paying_LTC/Public_Programs/Public_Programs.aspx)
For more information, go to eBenefits, a one-stop shop for information about VA benefits. The website, run by the Veterans Administration and Department of Defense, is designed for wounded warriors, veterans, service members, their families and those who care for them. Additional information is available from the National Hotline for VA benefits at 1(800) 827-1000.

BenefitsCheckUp. www.benefitscheckup.org. This is a comprehensive online resource for locating financial assistance programs that may help you pay for medications, health care, utilities, meals and other expenses. The website is developed and maintained by the National Council on Aging.

Long-Term Care Insurance. Long-term care insurance pays for long-term services and supports, most of which are not covered by traditional health insurance. Policies typically pay for nursing home care, home health, adult day services, respite care, and assisted living. The cost of your long-term care insurance policy is based on the type and amount of services you choose to have covered, how old you are when you buy the policy, and any optional benefits you choose, such as Inflation Protection.

_Long-term care insurance is not for everyone, and it is very important that consumers carefully evaluate the pros and cons and their own financial situation._ You should consider buying Long Term Care insurance if you have significant assets which you want to protect and can afford to pay the premiums. Contact the National Association of Insurance Commissioners at www.naic.org/Releases/2007_docs/long_term_care.htm to receive a free copy of “A Shopper’s Guide to Long Term Care Insurance.”

Private pay. You pay for services out of your own pocket.
CHAPTER 11: Financial and Health Care Planning

We don’t like to think about a time when we can’t make our own decisions, but advance planning for such a time is one of the best things you can do. By planning ahead, you can express what care you would want and ensure that decisions about your finances and care will be made by someone you trust.

To prepare for the future, you can create a document that (1) gives direction about the type of care and treatment you would want if you can’t communicate your wishes and/or (2) appoints someone to make those decisions on your behalf. To create such a document, sometimes called an **advance directive**, a person must have “capacity.” Basically, that means the person must be able to understand the nature of the document and to authorize someone else take care of his or her finances.

The key to good advance planning is discussing your values, beliefs and wishes with your family, friends, doctors, and other caregivers.

The rest of this chapter provides some very brief and general descriptions about some of the ways you can plan for the future and ensure that your wishes are carried out. **Beware** – Many legal documents have specific requirements, such as signatures, witnesses, etc. *The general descriptions below do not include all legal requirements.* Make sure you are aware of the requirements and follow them exactly.

**Financial Power of Attorney.** You can create a legal document to give another person (the agent or attorney in fact) the authority to handle a part or all of your financial matters. If you want the person you designate to continue to have authority to make decisions even after you lack capacity to make decisions for yourself, then you must include a statement to that effect in the document. You may also choose to have the power of attorney take effect only after you become incapacitated.

**Health Care Power of Attorney** also called **Medical Power of Attorney**. You can create a legal document in which you name another person - often called the health care proxy or health care agent - to make medical decisions when you are unable to do so as determined by your physician. Choosing your agent is important. You will need to think about your wishes and talk about them with your agent. That way you can be sure your agent knows your values and can be a good advocate. The power of attorney only goes into effect when you need it and can be revoked at any time if your ability to make healthcare decisions is restored. If you do not designate a health care agent and cannot make decisions for yourself, a legal proceeding will take place and a Guardian will be appointed to manage your financial and/or healthcare needs.
Living Will also called Declaration of Desire for a Natural Death. This is a statement that you desire not to have your life prolonged by extraordinary measures if you have a terminal or incurable illness or if you are in a vegetative state.

Advance Instruction for Mental Health Treatment. This document gives instructions regarding your mental health treatment and authorizes a mental health provider to act according to your wishes.

Declaration of an Anatomical Gift. Anyone over the age of 18 can donate organs by will, donor card or other document.

Do Not Resuscitate Order (DNR). This document is used to express an individual’s desire not to be resuscitated using cardiopulmonary resuscitation (CPR) or other mechanical means in the case of cardiac or pulmonary arrest. DNR forms are printed on bright yellow paper and are available through the NC Division of Health Services Regulation Office of Emergency Medical Services at http://www.ncdhhs.gov/dhsr/EMS/dnrmst.html

Medical Order for Scope of Treatment (MOST). The MOST is not a legal document but is a physician’s order instructing other health care providers what a patient’s wishes are regarding medical treatment at the end of life. It must be filled out by a qualified health professional who can explain various care and treatment options to the patient. Both the health care professional and patient must sign the form in order for it to be valid. The MOST is printed on bright pink paper, and forms are available for purchase by health care professionals through the NC Division of Health Services Regulation Office of Emergency Medical Services at http://www.ncdhhs.gov/dhsr/EMS/dnrmst.html

“Five Wishes.” You can use Five Wishes to express how you want to be treated if you are seriously ill and unable to speak for yourself. This document is easy to understand, and all you need to do is check a box, circle a direction, or write a few sentences. Once it is signed, witnessed, and your signature and those of your witnesses are notarized, your Five Wishes is a legal document. See: http://www.agingwithdignity.org/legal_North–Carolina.php

The NC Secretary of State’s office has an online Advance Health Care Directive Registry that allows you to download Health Directives Forms and a Donor Card form and then register them to help make sure that your doctor, family, and attorney are aware of your health care wishes.
CHAPTER 12: Resources for Family and Caregivers

While the focus of this guide is on you - the person receiving or planning to receive long-term services and supports - your family or friends may play an important role in your care. Their assistance may make it possible for you to remain at home, or they may help you in advocating for quality services - or both.

Caregiving can be rewarding as well as difficult and stressful at times. For that reason, your caregiver should know there are many resources available to support and assist him or her.

By contacting your local Area Agency on Aging, your caregiver can access the following services:

- Information to caregivers about available services
- Assistance to caregivers in gaining access to services
- Individual counseling
- Support groups
- Caregiver training
- Respite services
- Supplemental services on a limited basis, such as home-delivered meals

Most of these services are free.

A list of organizations that provide information/support to caregivers can be found in Appendix 1.
CHAPTER 13: Advocating for Quality Care: Selecting your Provider

By choosing the best possible provider from the very beginning, you greatly increase your chances of getting good care and services. Here are some important points to consider or information to gather during the selection process.

What is the provider’s track record?

- Research the provider’s history over time (a three-year period is helpful). See if the performance is consistently good, bad, or up and down.

- Effective in January 2009, the Division of Health Service Regulation established the Star Rating Program in response to requests by citizens for increased information regarding care in Adult Care and Family Care Homes. This tool provides information based on facility inspections and assists consumers in making informed decisions. Questions about the program can be directed to DHSR AdultCare.Star@lists.ncmail.net. A list of licensed Adult Care and Family Care Homes with their Star ratings can be found at www.ncdhhs.gov/dhsr. The star rating system makes it easier to spot an adult care home that has a bad track record. However, having 4 stars is not necessarily an indication of top quality.

- The federal government offers data about Medicare home health agencies and Medicare/Medicaid nursing homes on its website:
  
  Home Health Compare http://www.medicare.gov/HHCcompare
  Nursing Home Compare http://www.medicare.gov/NHCompare

Does the provider do background checks on individual direct care workers?

Ask the provider if they conduct a national criminal background check or a state background check on all their employees.

If you are hiring your own attendant/aide, ask the individual to provide you with a national criminal background check or state background check (at your expense). If there are any arrests or convictions, you can evaluate the nature of those convictions and make your own decision.

Who does the provider serve?

Don’t assume that the provider will serve everyone. Ask if there are any age limits or other limitations on who can receive services.
What care/services are provided?
Ask for a list of exactly what services are included in the rate you are paying. Also ask for the cost of other add-on services that are not included in the base rate. Do the best you can to “drill down” and get details.

Disclosure forms: An increasing number of states are requiring assisted living facilities and any center/facility providing “dementia special care” to complete disclosure forms. These forms can be very helpful because they give more detailed information and a way to compare one facility to another. In some states, CCRCs must also provide disclosure forms that inform you about a facility’s financial status. Ask your local long-term care ombudsman if your state requires such disclosure forms. If so, request this form if it isn’t given to you.

Contracts: Ask for a copy of the contract or agreement and review it before you sign. In some settings, such as assisted living, the contract is the only way to really know what is provided and the costs. In both assisted living facilities and CCRCs, review contracts carefully to see under what circumstances you may be asked to move from your unit.

What is the provider’s expertise and experience?
Ask providers about their expertise and experience with the services you are asking them to provide. How long have they provided this type of care/service?

Will the provider accommodate your needs, preferences and routines?
Discuss your needs and any particular preferences or routines that are important to you with the provider. Ask the provider if they will accommodate those needs and preferences and how. In addition, ask who determines when you need more services or when the services provided can no longer meet your needs – you or the facility.

Does the provider practice person-centered care?
Ask how the provider practices person-directed care. Ask them to tell you how they will learn what is important to you and how they will honor your choices.

Does the provider offer memory care?
If the provider claims to offer “memory care,” ask what they mean by this term. What does “memory care” involve? What makes it different from other care? What training does the provider have in memory care or working with individuals with memory loss, confusion and/or behavioral symptoms?

How does the provider obtained informed consent?
Will the provider obtain your informed consent before administering any
psychoactive drugs, such as sedatives or anti-psychotics? How will the provider document the consent? Will the provider obtain consent from your legal guardian or power of attorney if you lack capacity to give consent?

What are the provider’s staffing levels?
If you are considering receiving care in a facility, ask what the staff-to-resident ratio is. Ask about the daytime and nighttime ratios. The fewer residents a nurse, aide, or other staff person has to care for, the better!

Does the provider have regular staff assignments?
Ask if the same attendant/aide will be assigned to you each time. This is called “consistent assignment” and has been shown to result in better care/services and increased satisfaction for both the person receiving and providing services.

Will the provider’s location be a problem?
If you are receiving services at home, how far the provider lives from you can impact his or her ability to assist you when the weather is bad and transportation is difficult. In residential settings, such as an assisted living/group home or a nursing home, the facility’s distance from your family and friends will affect their ability to visit you.

Does the provider have good references?
Request at least three references from consumers or family members who have used the provider’s services for some time. Don’t be dissuaded if the provider says they don’t usually provide references. Like any good business, they should be able to provide references from satisfied customers.

Visit the center or home! Take any formal tour the provider may offer, but try to go back unannounced several times, including evenings and weekends. Observe and spend time getting a feel for the center or facility. If possible, speak to any current residents and any family or friends who may be visiting. In facilities, ask to taste the food.

Additional Tips. There are many checklists you can use to assist you in evaluating a provider. These help you ask questions you may not otherwise have thought about. If you have online access, you can search for checklists by entering “assisted living facility checklist” or “home health agency checklist,” etc. You can also contact your local Area Agency on Aging.
CHAPTER 14: Advocating for Quality Care: Being Proactive

The best way to achieve quality care and services is for you and your provider to come together as a team. Your provider brings skills, health care knowledge and expertise to the team, while your expertise is YOU. No one knows more about you than you, and no one cares more!

By actively participating in and monitoring your care and services, you can help ensure quality. Here are some steps you can take.

**Know the full range of care/services/supports for which you are eligible.** Ask for a written description of all the services to which you are entitled. Far too often people don’t receive all the services they need because they aren’t aware that they have the right to receive those services.

**Learn about your medical condition, if appropriate.** Educate yourself about the symptoms of your condition, its treatment or management, and its progression over time if appropriate. The more you know, the better equipped you are to ask questions and shape your care.

**Learn what you have the right to expect.** It is critical that you know your provider’s responsibilities. You can find out a provider’s obligations by:

- Reading the regulations if the provider is a center, agency, home or facility that is state licensed or Medicaid and/or Medicare-certified. In most states, the regulations are available online.

- Reviewing the contract or agreement you signed at the start of services or the time of admission. In cases where the provider is not licensed or certified, the contract is the only place where the provider’s responsibilities will be stated.

**Learn what your rights are.** You can’t exercise your rights if you don’t know what they are! Your rights might depend on your situation. For instance, if you are a person with a physical disability living in an apartment and receiving services under a Medicaid Waiver, your rights will include 1) rights regarding the type of services and number of hours of services you receive; 2) rights pertaining to your housing under the Fair Housing Act and other anti-discrimination laws; 3) rights regarding appeals, choice, confidentiality, consent, providers, records, planning, wait lists and written notice; and more. An older adult receiving rehabilitation services under Medicare in a nursing home will have a broad range of rights pertaining to the care and services provided by the nursing home and rights related to Medicare. **Ask your provider for a copy of your rights.**
Create a circle of support. A circle of support is a group of family members, friends and/or other people you trust who provide assistance, guidance, relationships, safety and community to you. Members of your circle of support can assist you in advocating for the care and services you want, suggest steps you might take relating to your care, serve as a sounding board, and provide encouragement.

Provide information about yourself to your providers. The more your providers know about you, the better job they can do of giving you care and services in a way that meets your needs and respects what is important to you. Make sure to tell them how you like care to be done, when you want your care and services provided, your routines, preferences, likes and dislikes. Consider putting this information in writing, giving a copy to your provider and keeping a copy where you can access it easily.

Participate in developing your care/service/support plan. With a few exceptions, you will have a care plan, service plan or support plan. In general, such a plan outlines your goals; your abilities and needs; who will provide services; and what care, services and supports will be provided to meet those needs and maintain or further develop those abilities in a way that supports your normal routines, choices, and preferences.

If the development of a plan is not required by regulation, you should consider creating one with your provider anyway. It is always helpful to be clear about exactly what services will be provided to meet your needs and goals. The plan should be reviewed on a regular basis or if there is a major change in your condition. Ask your provider how frequently the plan will be reconsidered.

Suggestions for developing a care/service/support plan:

- Inform your provider that you want to be involved in developing your plan.
- If you have more than one aide/attendant, ask the person who is most familiar with you and whom you trust the most to participate.
- Prepare for the discussion by identifying any questions, comments or concerns you have. Make a list so you remember the points.
- Speak up at the meeting! Tell your provider what you want and need.
- Ask for a copy of the plan after it has been created or revised.
- Monitor that the plan is being followed.
- Request a change/revisions if you are not happy or your condition changes.

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8 Caregiver Digest: A Guide to Indiana Long Term Care Resources. United Senior Action Fdn.
Ask for the same aides/attendants every time you receive care and services (consistent assignment). When the same people assist you on an ongoing basis, they become familiar with your needs, preferences and how you like things done. This results in better care and services for you. It also helps you and your aide/attendant develop a solid relationship, which makes both of you more satisfied.

Get to know your aides/attendants and treat them with respect and appreciation. Just as your aides/attendants will try to get to know you, you should make an effort to get to know them as well. Show them that you are interested in and care about who they are as people.

Be polite, respectful and considerate. Practice the “golden rule: Do unto others as you would have them do unto you.”

Show appreciation. Caregiving can be a hard job and often pays very poorly. Saying “thank you” frequently can make a big difference in how a worker feels about their job – and in the quality of care and services you receive.

Know what care/services you are supposed to receive according to your care/service/support plan. The only way to ensure you get all the care/services stated in your plan is to know exactly what your plan says. Getting a copy of your most recent plan allows you to do this.

In addition, know what medications you need to take and when and what they look like. This helps prevent medication errors.

Communicate effectively.

- Ask questions if something is unclear.
- State what you mean clearly, politely, respectfully and in language that is free of blame and judgment. Speak up nicely if something isn’t done, or if it isn’t done the right way. How you communicate is just as important as what you communicate.
- Show appreciation. Remember to thank staff when a problem has been addressed or when good care has been provided.

Monitor care/services. Overseeing your own care and services is critical in ensuring that you receive the right care and services in the right way at the right time.
**Review records kept by the provider.** Almost all providers are required to maintain records regarding your care and services. Most providers develop assessments and reports that include information about the services provided, adequacy of services, progress with goals and objectives, your satisfaction with services and other individual and personal information.\(^9\) Because written documentation can influence the quality, type and amount of services you receive, you should review these records periodically for accuracy.

**Don’t be surprised** if your provider wants to know why you are asking to look at your records. Most consumers don’t know they have the right to see their records, so providers don’t receive many requests. When they do receive a request, it’s a bit out of the norm. Simply tell your provider that you want to work with them as part of a team. Being an active participant in your care and services and reviewing your records is one of the ways you can do that.

**Request your own copies** of key records and keep any documents or paperwork you receive related to your care/services.

**Trust, but verify.** If your provider tells you they can’t do something because the “state” or the “rules” won’t let them, ask them to show you where it says in writing that something can’t be done. Sometimes staff have misunderstood a regulation or mistakenly thought a rule existed when it didn’t.

**Keep notes.** You should keep your own records of your care and services. It is particularly important to document any incidents or problems that arise. Indicate the date and time of the incident or problem, what happened, where it happened, who was involved and their names and what the provider said they would do about the problem or incident. In the event that the problem is not solved or the incident occurs again, your documentation can help if you have to go up the chain of command or request outside assistance.

**Know whom to contact within the agency, facility, or system when you have questions/concerns about your care/services.** Find out from the very beginning the person to turn to if you have any questions and the best way to reach them. For example, you might talk to your care manager or service coordinator in the community or the social worker in the nursing home.

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\(^9\) Home and Community-based Services for People with Disabilities: Medicaid Waiver Services Guide. Virginia Board for People with Disabilities.
**Know that you can change providers if you are not happy with care/services.**
You do not have to continue receiving services from the same provider if that provider is not meeting your needs. You have the right to change providers at any time. However, this may not be easy if there is a lack of providers in your area or if providers don’t feel they can meet your needs. In those situations you may have to wait a while, or even consider a provider outside of your community.

**Know what advocates are available to guide/counsel you.** There are a range of advocates who can give you advice and suggestions about your care and services and answer questions free of charge. These individuals don’t work for the provider and can give you unbiased information and guidance. Below is a list of some of the key advocates.

**Advocates available in North Carolina:**

*Long-term care ombudsman* – advocate for residents in nursing homes and adult care homes

*Centers for Independent Living* – non-profit organizations that are consumer driven and controlled that provide programs and services for people with disabilities

*Disability Rights NC* – federally mandated protection and advocacy system

*Friends of Residents in Long-Term Care* – non-profit citizen advocacy group, [www.fortlc.org](http://www.fortlc.org), 919-782-1530
CHAPTER 15: Advocating for Quality Care: Addressing Problems

Problems can arise in any setting because no provider is perfect – just as none of us is perfect. While you can’t expect perfection, you can – and should – expect your provider to respond to and do whatever they can to address your concern.

This section discusses approaches you can take to resolve problems. The strategies are not listed in any order.

Before you communicate your concern to anyone, start by gathering the details of the problem. The more information you have, the easier it will be for the provider to try to address the concern.

As appropriate, include the specifics, such as when and where the problem occurs and who is involved. If you have a major concern, particularly one that is ongoing, it can help to write up a description of the problem before you talk to someone. This makes it easier to communicate later. Describe the facts of the situation, using objective language.

In addition, before speaking up, evaluate how you talk to staff and managers about concerns. As mentioned earlier, how you communicate is just as important as what you communicate. Avoid blaming individuals. The way you express your concern can build a bridge – or a wall. Here are a few tips.10

**Fear of Retaliation.**

No matter where people receive care and services, the fear of retaliation is very real. Individuals are often afraid to speak up about problems or concerns because they are afraid they will make an attendant/staff person/provider angry, and this anger will result in retaliation. Retaliation can often be very subtle – like making you wait to be taken to the bathroom. It is also hard to prove.

Connect with the long-term care ombudsman, the Centers for Independent Living, your local legal services program (http://www.lsc.gov/; (202) 295-1500) or some other outside advocate. Retaliation may be prevented if the ombudsman or other advocate tells the provider they expect the problem will be resolved, and they will be monitoring the situation closely.

10 Working for residents, by working with families. National Long-Term Care Ombudsman Resource Center.
While retaliation can and does exist, here are some points to consider:

- **The fear of retaliation is often greater than its actual occurrence.** It’s important to weigh your concern about what might happen with your concern about what is happening right now.

- **Retaliation does not happen as often as people fear.** There is certainly no guarantee that retaliation won’t occur, but there is the guarantee that nothing will change or improve if you don’t speak up.

- **Speaking up often results in better care and services rather than in retaliation.** Frequently the “squeaky wheel” really does get the “grease.”

- Building positive relationships with staff can reduce the likelihood of retaliation.

**Communication Tips:**

**Ask open-ended questions.** These questions can build rapport as well as provide you with information. Example: “Can you help me understand the delay in answering my call light?”

**Use reflective listening.** Reflective listening or responding is the process of restating in our own words the content and/or feeling of what someone has said. It shows that you are truly listening and trying to understand the other person. Example: Your attendant has missed several days of work because her car keeps breaking down. She tells you she doesn’t have enough money to fix the car right now, and the people who promise to give her a ride keep forgetting. She says she hopes you’ll understand. You might say, “You’re frustrated because you’re having problems with your car. You feel that you’re doing everything you can to get here and hope that I will be patient during this time.”

**Utilize the power of “we.”** When you say “we” in your conversation, it creates a sense of team and partnership between you and your provider. This sends a message that you both working together to ensure good care and services. Example: “Can we talk about what we can do to address this issue?”

Two very helpful handouts on communication by PHI are *Guidelines for Presenting the Problem* and *Coaching-based Communication*. These handouts discuss ways in which problems can be presented respectfully and effectively. They can be found in Appendix 4 and Appendix 5.
**Problem-solving Approaches:**

- Speak to the attendant/staff person most directly involved. If the issue relates to something the attendant/staff person can control, it may be possible to resolve the matter at this level. Document your conversation.

- Talk to the staff person you were told to contact with any questions/concerns (see previous section). If you don’t know who that person is, start by speaking with the agency/facility social worker or service coordinator (employed in public housing), or ask who the best person is to contact.

- Follow agency/facility policy for grievances. Find out if the agency or facility providing care/services to you has a grievance policy (it may be called something else) and what the policy is. Then follow the policy. The strength of this approach is that you are using the entity’s own process. You can usually express your concern orally or in writing. If you voice your complaint verbally, it is a good idea to also submit it in writing. This way your concern is communicated as you described it and with all the detail. Make sure to keep a copy of your written concern.

- Ask a family member, friend, or member of your circle of support to give you suggestions on how to proceed and to be with you when you are voicing concerns. It’s always helpful to get feedback and support from others.

- Ask for a special care/service plan meeting to discuss your concerns. Make sure that someone with the authority to change things attends.

- Document all conversations. Keep copies of any correspondence you receive.

- Go up the chain of command. If speaking to the attendant/staff person most directly involved is not successful, work your way up. Speak to the supervisor, the administrator/director/manager of the agency or facility, and, if necessary, the person to whom the administrator/director/manager reports.

- Unite with others who share the same concern.

- Many nursing homes, assisted living facilities, group homes, continuing care retirement communities and public housing buildings have resident councils (these may be called self-governance councils).
• A resident council is a group of residents who work together to improve the quality of care/services, conditions and quality of life of all residents living in the facility or building. To find out if your facility has a resident council, ask the social worker, service coordinator, or manager. If there is a resident council, ask the council president to discuss the problem at the next meeting. If other residents are experiencing the same problem, the council can bring the issue to the attention of the administration. When there is “strength in numbers,” the concern is more likely to be addressed.

• If your facility does not have a council, consider starting one. The ombudsman can help you form a council in a nursing home or assisted living facility. You can obtain information on council development by calling (202) 332-2275 or going to: www.theconsumervoice.org

• Join with others who receive care and services from the same provider. If you are receiving services in your home, it is still possible, although more difficult, to connect with other consumers. If a case manager is coordinating your services, you can ask him or her to give your name, contact information, and a request to call you to other clients being served by the same provider.

• Be a “networker” and attend support group meetings or conferences held by groups such as the National Multiple Sclerosis Society or the Alzheimer’s Association. This gives you the opportunity to meet people receiving similar services who might have the same provider.

• Advocacy organizations, such as Friends of Residents in Long-Term Care, might also be of assistance.

Other avenues to pursue to solve problems:

Many people successfully resolve their concerns using the above approaches. Sometimes, however, you may need to turn to outside organizations.

Long-Term Care Ombudsman Program. Long-term care ombudsmen serve as advocates for residents of nursing homes and assisted living facilities. Their services are free and confidential. Long-term care ombudsmen work to ensure the health, safety, welfare, and rights of residents by:

• Investigating/working to resolve complaints, concerns or problems voiced by residents or their representatives
• Providing information about residents’ rights and facility responsibilities
• Working for improvements in the long-term care system

In North Carolina the Ombudsman program is located within the Division of Aging and Adult Services. To find contact information for your long-term care ombudsman, go to www.ncdhhs.gov/aging/ombud.htm or call (919) 733-8395.

Other ombudsman programs. The Brain Injury Association of North Carolina (BIANC) has been recruiting and training a network of family members of persons with brain injury to serve as Ombudsmen to the Division of MH/DD/SAS. They are assigned to assist families/consumers who are served by one of the four regional Family and Community Support Centers find resources, information, and support. Contact information for the ombudsmen can be found through the BIANC Helpline at 800-377-1464.

Care managers. Care managers can also help to resolve problems. A private geriatric care manager will advocate on behalf of both older adults and persons with disabilities and brings knowledge and expertise to a problem. Private geriatric care managers charge a fee for their services and most will also bill for out-of-pocket expenses, such as mileage. To get a list of private geriatric care managers in North Carolina, go to: www.caremanager.org or call (520) 881-8008.

If your services are funded through the Medicaid Waiver or a state-funded program, you will most likely have a case manager or care manager assigned to you. In many cases, the case manager will work with you and your provider to resolve a problem.

Centers for Independent Living (CIL). CILs are organizations that provide services to maximize the independence of individuals with disabilities. They offer individual advocacy that may help you in resolving a concern. To learn what CIL is closest to you, go to: http://www.virtualcil.net/cils/ or call (877) 525-3400.

Protection and Advocacy Services (P&A) Disability Rights NC is a federally mandated agency which works to address concerns about care/services, rights, access to services and more for people with disabilities both in residential or community settings. Visit its website at www.disabilityrightsonc.org or call (877)-235-4210.

State agencies that oversee/regulate the provider. The Division of Health Service Regulation licenses and certifies programs that provide care and treatment. The agency investigates complaints about care, services, rights and other issues. Information may be found on the web at www.ncdhhs.gov/dhsr
Additional state agencies/entities you can contact for assistance include:

- Adult Protective Services
- Medicaid Fraud Control Unit
- Licensing boards
- Quality Improvement Organizations
- Law enforcement
- Legal assistance programs

Descriptions and contact information are provided in Appendix 1.

**Problems with an attendant you hired.** If you run into problems with an attendant whom you have hired and are paying completely out of your own pocket, there are fewer options to pursue. Nevertheless, the following approaches may help you address your concerns.

- Use good communication skills to review your expectations with your attendant. Follow the points discussed in the two handouts in Appendix 4 and Appendix 5.
- Remember, if things really aren’t working out, you can fire the attendant. While this is certainly not pleasant, it may be the best solution for both you and the attendant.

**Problems with care/services being reduced, terminated or not paid for.**

Sometimes the problems consumers face relate to services being cut, stopped, or not covered.

You should always receive some type of written notice before there is a change in service. Examples of such changes include decisions to cut the number of hours of attendant care you receive weekly, stop physical therapy in a skilled nursing facility or not pay for a service you think should be covered. The notice will tell you how you can appeal if you disagree with the decision. Consumers often win these appeals. The local legal services program may provide help with these appeals. You can also check with the local long-term care ombudsman program or CIL.

One problem consumers sometimes encounter relates to **Medicaid recertification**, sometimes called “reassessment.” This is the process in which the Medicaid program determines if you are still eligible for Medicaid. It requires you, or someone on your behalf, to submit required paperwork. If you fail to comply with the requests for documentation, you may be at risk of losing your services, at least for a little while.

You can avoid problems with Medicaid recertification by being proactive. Know when your paperwork is due and keep on top of it! Before the state terminates your services,
it should send you a pre-termination notice and give you a chance to appeal. If you appeal promptly, you will generally be able to keep your benefits and services until the appeal is decided. This gives you more time to demonstrate that you continue to be eligible for Medicaid. If you need help with an appeal, your local legal services agency may be able to assist you.

**For Medicare beneficiaries:**

Medicare beneficiaries are increasingly facing a problem with the requirement that they have a three-day hospital stay in order for Medicare to pay for rehabilitation in a skilled nursing facility. Instead of being admitted to a hospital, beneficiaries are being placed in "observation status." Their hospital stay is considered outpatient observation and therefore does not count toward the three days. Beneficiaries who go from the hospital to a skilled nursing facility are then informed that Medicare will not pay for their nursing home stay because the three-day requirement was not met.

For information about how to address this issue, and other Medicare coverage problems, like therapy services being terminated in a skilled nursing facility because you are not "improving," contact the Center for Medicare Advocacy at (860) 456-7790 or [http://www.medicareadvocacy.org/](http://www.medicareadvocacy.org/). The SHIIP program may also be able to help. See Chapter 10 and Appendix 1 for information on the SHIIP program.
CHAPTER 16: Advocating for Quality Care: Improving the Long-Term Care System

While progress has been made in developing and providing a range of readily available and affordable quality long-term services and supports across the country, there is still a long way to go. Far too many individuals are still forced into nursing homes because there are no other affordable options in their communities, and quality of care and services at home or in a residential setting is uneven at best.

Current advocacy efforts at the national level include:

- Balancing the long-term care system so that more home- and community-based services are available to consumers. Currently Medicaid, which funds the majority of long-term services and supports, is mandated to pay for institutional or nursing home care in every state. Home and community-based services, however, are optional. As a result, many consumers cannot choose where, when, and how they receive services.
- Moving people out of institutions and into the community so that they can live in the most integrated setting possible.
- Implementing new nursing home provisions under the Affordable Care Act (also known as the health reform law). These include providing better information to consumers about nursing home ownership, staffing, inspections, and more; improving the complaint investigation process; and better protecting residents' families and legal representatives from retaliation.

In the previous sections of this guide, you learned ways to self-advocate to improve your care/services. You can also advocate for improvements in the care and services available to everyone in your state or across the country.

There are several ways you can advocate for changes in the long-term care system. You can do this on your own by contacting your state and federal policymakers and sharing any concerns or ideas for improvements you have about the system.

Legislators pay attention when they hear from their own constituents!

You can also make a difference by getting involved in an advocacy organization. These groups keep you informed about critical policy issues and how you can take action, often just by making a telephone call or sending an email to policymakers.

A list of some of the national and state advocacy organizations can be found in Appendix 1.
Appendix 1: Resources

The list of resources in this section is designed to direct you to more in-depth information about a number of the topics covered in this guide. The list is not intended to be complete and comprehensive. Instead its purpose is to take you farther down the road on your long-term care journey.

**Advocacy Organizations**

These are just a few of the many other organizations that provide consumer information, protection, advocacy, resources and/or services.

**AARP** is a national organization representing individuals age 50 years or older. Among its many and varied activities and services, AARP advocates at both the state and national levels and provides information on a wide range of topics. Its Caregiver Resource Center provides educational materials on long-term care, including living at home, assisted living, nursing homes, and continuing care retirement communities and tools such as the Long Term Care Calculator. Contact: [www.aarp.org](http://www.aarp.org), (888) 687-2277, TYY (877) 434-7589. In North Carolina, the contact information is [www.aarp.org/states/nc](http://www.aarp.org/states/nc), (866) 389-5650

**The Alzheimer’s Association** provides information, education, support and services to individuals with Alzheimer’s and their families. One of the tools offered by the Association is CareFinder, an interactive online program that provides consumers with recommended long-term care options based on answers consumers provide about their needs, abilities and preferences. The Alzheimer’s Association also conducts both state and federal advocacy. Contact: [www.alz.org](http://www.alz.org), (800) 272-3900, TDD: (866) 403-3073

**Alzheimer’s North Carolina Inc.** provides family support, community education and public awareness about Alzheimer’s disease, and currently serves 51 of North Carolina’s 100 counties. Alzheimer’s North Carolina raises funding to support research into the cause, treatment, prevention and cure of Alzheimer’s disease and related dementias. Contact: [http://www.alznc.org](http://www.alznc.org), (919) 832-3732 or (800) 228-8738

**The Alzheimer’s Foundation** provides education, such as written materials; conferences and workshops; social services, such as counseling, support groups, early stage stimulation programs, and social model adult day services; and advocacy at both the state and national level. Contact: [www.alzfdn.org](http://www.alzfdn.org), (866) AFA-8484

**The Arc** is a national community-based organization advocating for and serving people with intellectual and developmental disabilities and their families. In addition to advocacy, many of The Arc’s state and local chapters offer supports and services such as job training, supported employment, transition planning, supported living, an respite care. The Arc also provides information such as factsheets and publications. Contact: [www.thearc.org](http://www.thearc.org), (800) 433-5255. The contact information for NC is [www.arcnc.org](http://www.arcnc.org), (800) 662-8706
The Association of University Centers on Disabilities (AUCD) advocates for persons with disabilities. Contact: http://www.aucd.org/, (301) 588-8252

Autism Society of NC supports individuals with autism and their families through advocacy, education, and direct services. The organization provides day support, residential services, personal care, respite, caregiver training, supported employment, and operates a summer therapeutic camp. Contact: www.autismsociety-nc.org, (800) 442-2762

Bazelon Mental Health Law Center advocates for people with mental illnesses. Contact: www.bazelon.org, (202) 467-5730

Brain Injury Association of America (BIAA) promotes awareness, understanding and prevention of brain injury through education, advocacy, and research. Contact: www.biausa.org, (703) 761-0750

Brain Injury Association of NC (BIANC) - offers an ombudsman program, legislative advocacy, education and training to consumers, families, state agencies, and service providers as well as prevention activities, support groups, camps. Community Support Centers are located in Asheville, Charlotte, Greenville, Raleigh, and Winston-Salem. Contact: www.bianc.net and the Family Helpline at (800) 377-1464

Disability Rights Network advocates on behalf of people with disabilities. Contact: www.napas.org, (202) 408-9514, TTY: (202) 408-9521

Disability Rights NC is a federally mandated protection and advocacy agency which works to address concerns about care/services, rights, access to services and more for people with disabilities both in residential or community settings. Contact: www.disabilityrightsnc.org or call (877) 235-4210.

Easter Seals/UCP provides direct services and supports through a network of sites across the country and conducts education, outreach and federal and state advocacy. Its website has information to help consumers better understand different disabilities and services such as physical and occupational therapies. Contact: www.easterseals.com, (800) 221-6827.

In North Carolina, Easter Seals and United Cerebral Palsy have combined their services www.nceastersealsucp.com, (800) 662-1179 and provide direct services such as housing, therapy, and community living. CP has developed a comprehensive set of state-based guides called “One-Stop Resource Guides” that help locate assistance, information and resources for people with disabilities. To access the guide, go to http://www.ucp.org/ucp_generaldoc.cfm/1/3/43/43-43/5807

Friends of Residents in Long Term Care advocates for policy changes to advance quality of life in long-term care. Contact: www.forltc.org, (919) 872-1530

National Alliance on Mental Illness (NAMI) is a national grassroots mental health advocacy organization dedicated to improving the lives of individuals affected by mental illness and their
families. NAMI focuses on raising awareness, education and national and state advocacy. In addition NAMI provides services such as an information helpline and support groups and information about mental illnesses, mental health care, diagnosis, treatment and recovery. Contact: www.nami.org, (800) 950-NAMI, and in North Carolina, the contact information is www.naminc.org, (800) 451-9682

**National Association of Area Agencies on Aging (n4a)** represents Area Agencies on Aging and champions Title VI Native American aging programs. It supports the national network of Area Agencies on Aging and Title VI programs through advocacy, training and technical assistance. On its website, n4a has a consumer section with consumer publications and access to the n4a Senior Housing Locator. Contact: www.n4a.org, (202) 872-0888

**National Association of States United for Aging and Disabilities** advocates on behalf of older adults and persons with disabilities Contact: www.nasaud.org, (202) 898-2578

**The National Consumer Voice for Quality Long-Term Care** advocates on behalf of long-term care consumers in all settings. Contact: www.theconsumervoice.org, (202) 332-2275

**National Council on Aging (NCOA)** is a service and advocacy organization that is a voice for older adults in greatest need and the organizations that serve them. NCOA works to improve the health of older adults, enhance their economic security, promote their independence and dignity and strengthen the community organizations that serve them. NCOA advocates at the national level and educates and informs older adults about laws and policies that affect long-term care and other aspects of their lives. It also offers BenefitsCheckUp (see description under “Paying for Long-Term Care”). Contact: http://www.ncoa.org/, (202) 479-1200

**National Empowerment Network (NEC)** assists people with mental illness with recovery and to empower them. NEC provides information and referral services; educational materials on advance directives, self-help techniques, legal services and other topics; and support groups. NEC also advocates at the local, state and national levels. As part of its advocacy, NEC organizes and develops consumer-run organizations and helps them and others gain the knowledge and skills to create a more recovery-oriented and consumer and family-driven mental health service system. Contact: http://www.power2u.org/, (800) 769-3728

**The National Senior Citizens Law Center (NSCLC)** promotes the independence and well-being of low-income elderly and persons with disabilities through advocacy, litigation and the education and counseling of local advocates. NSCLC also provides consumer information and publications on home care, assisted living and nursing home care and services. Contact: www.nsclc.org

**NC Mental Health Consumer Organization** is operated by and for individuals who have a personal experience with mental illness. Contact: www.ncmhco.org, (800) 326-3842

**North Carolina Stroke Association** is focused on reducing the incidence and impact of strokes through screening, education, outcome assessment, and advocacy. Contact: ncstroke.org, (336) 713-5052
Self-Advocate Leadership Network is a collaboration between self-advocates from across the country and the Human Services Research Institute (HSRI). Its purpose is to help people with developmental disabilities become strong self-advocates. The Network offers toolkits and training to provide self-advocates with the skills and tools to gather information on what is happening in a state’s developmental disabilities system, conduct an analysis of the system and work for needed changes. Its “My Voice, My Choice” is a curriculum that teaches persons with developmental disabilities to be self-advocates and become active participants in local and statewide systems change and in planning their own services and supports. Contact: http://www2.hsri.org/leaders/,(503) 924-3783

Assessment Tools

The tools listed below can help you identify the type of long-term care assistance you may need now or in the future.

Medicare Chart
http://www.medicare.gov/LongTermCare/Static/Step1.asp?dest=NAV%7CSteps%7CStepsOverview%7CStep1

New Mexico Person-Centered Planning Tool
http://www.nmresourcedirectory.org/
Note: Although this tool refers to some New Mexico state agencies, programs and services, the questions and the information it gathers apply in any state.

Complaint Resolution

Adult Protective Services (APS)
Adult Protective Services investigators investigate reports of abuse, neglect or exploitation of endangered adults. Most APS programs serve both older and younger vulnerable adults. However, in some states, APS is responsible only for cases involving older adults, while a few APS programs serve only younger adults ages 18-59. In addition, APS does not conduct investigations in nursing homes in some states. Adult Protective Services falls under the NC Division of Aging, but complaints are handled locally by county Departments of Social Services.

Medicaid Fraud Control Unit
The duties of this unit include investigation of abuse and neglect of residents of long-term care facilities and theft of residents’ personal funds. Contact: http://www.ncdoj.gov/About-DOJ/DOJ-Contact-Information.aspx, (919) 881-2320

Elder Law Firms
Private attorneys can often help get a problem resolved, help with an appeal and assist you in seeking compensation and justice when you’ve been harmed or neglected by a provider. “Elder law” attorneys may be most helpful in this regard as they focus their practice on issues frequently confronted by older adults, persons with disabilities, and their families.
To locate an elder law attorney in your area, go to: www.naela.org/MemberDirectory/.
Legal Services Corporation, Inc.
Legal Services Corporation programs offer a wide range civil legal assistance to those
who meet certain financial criteria. For more information, go to http://www.lsc.gov/
(202) 295-1500.

Senior Legal Hotlines
Free legal telephone advice is provided to people over 60 years of age in a number of
states. Go to: http://www.legalhotlines.org/ to learn more. In N.C., contact Legal Aid at
(919) 856-2564.

Culture Change

The Pioneer Network is made up of consumers, providers, health care professionals, direct-care
workers and others who want to promote culture change. The Pioneer Network website provides
information and materials on culture change, including a consumer guide for finding a nursing
home that has adopted culture change. Contact: www.pioneernetwork.org, (312) 224-2574

Culture Change in Nursing Homes Factsheet
The National Consumer Voice for Quality Long-Term Care (Consumer Voice) offers a factsheet
discussing the principles of culture change. Available at:
http://www.theconsumervoice.org/sites/default/files/advocate/Culture-Change-in-Nursing-
Homes.pdf

Family/Caregiver Resources

Family Caregiver Alliance (FCA) is a national organization that serves as a public voice for
caregivers. FCA provides education and information to caregivers, and conducts research and
advocacy. FCA houses the National Center on Caregiving (NCC) that is a great source of
information on caregiving and other long-term care issues. The NCC in turn, offers the Family
Care Navigator that allows caregivers to locate support services in their communities. Contact:
www.caregiver.org, (800) 445-8106

National Alliance for Caregiving (NAC) is a coalition of national organizations focusing on
issues of family caregiving. The goal of the Alliance is to improve the quality of life of families
and individuals receiving care and services. The Alliance has numerous brochures, booklets and
other publications useful to family caregivers. Contact: www.caregiving.org

In addition, NAC’s Family Care Resource Clearinghouse find reviews and ratings of hundreds
of books, videos, websites, magazines, fact sheets and other resources addressing the range of
issues and questions faced by family caregivers. To contact the Alliance, send an email to
info@caregiving.org or write to National Alliance for Caregiving, 4720 Montgomery Lane, 2nd
Floor, Bethesda, MD 20814. No phone number listed.
**Becoming An Effective Advocate for Care.** MetLife Mature Market Institute in cooperation with the National Alliance for Caregiving has established a guide designed to help family caregivers learn how to be strong and effective advocates for someone they love in any setting. It includes tips on talking to doctors, communicating with insurance companies and getting good care at home, in assisted living or in a nursing home.


**Next Step in Care** is a website filled with resources to help family caregivers work better with health care professionals to plan and carry out smoother, safer transitions of a loved one between health care settings (home to hospital, hospital to nursing home or home, etc). The website provides guides and checklists to help families ask questions to avoid miscommunication and errors and to ensure the best possible transition. Contact: [http://www.nextstepincare.org/](http://www.nextstepincare.org/)

**Financial and Health Care Planning**

**American Bar Association (ABA)**


The American Bar Association has written a number of publications for consumers about health and financial decision making. These include “Health & Financial Decisions: Legal Tools for Preserving Your Personal Autonomy,” “Myths and Facts about Health Care Advance Directives,” “Advance Planning Resources,” and more. To access the list of publications, go to: [http://new.abanet.org/aging/Pages/Onlinepublicationsconsumers.aspx](http://new.abanet.org/aging/Pages/Onlinepublicationsconsumers.aspx)

**Hospice**

**Medicare Hospice Benefits**

Center for Medicare and Medicaid Services


This guide describes hospice care, the Medicare hospice benefit, and finding a hospice program.

**Housing**

**n4a Senior Housing Locator**

The National Association of Area Agencies on Aging (n4a)’s Senior Housing Locator is a tool for assisting seniors, their families and others to find appropriate senior housing options anywhere in the country. The website also provides information about the different housing options available, home care and hospice services, legal assistance, transition coordination and more. Contact: [http://www.seniorhousinglocator.org/](http://www.seniorhousinglocator.org/)

**Housing Options for Older Adults: A Guide for Making Housing Decisions** This booklet provides an overview of the many housing options available across the country. It also discusses key benefits and challenges to consider for each housing option and describes the primary legal considerations relevant for each option. To receive a copy of the booklet, call the Eldercare Locator at (800) 677-1116 or download it at:

Disability.gov
http://www.disability.gov, click on “Housing”
The “Housing” section of this website has information about housing rights, tax credits, making a home accessible, and supportive housing services that can help people with disabilities live independent, self-directed lives.

Paying for Long-Term Care

BenefitsCheckUp. A comprehensive resource for locating financial assistance programs that may help pay for medications, health care, utilities, meals and other expenses. The website is developed and maintained by the National Council on Aging. www.benefitscheckup.org

Medicaid Reference Desk is a resource for people with intellectual disabilities and their families to learn about Medicaid and other public benefits, services and supports. Information about Medicaid programs, eligibility and services is provided for every state. While this resource is intended for people with intellectual disabilities, it can be helpful to other consumers. Contact: http://www.thedesk.info

Senior Health Insurance Information Program (SHIIP). The Senior Health Insurance Information Program is a free counseling program. Trained counselors provide answers to questions related to Medicare, Medicare Supplement Insurance, Medicare Advantage, Medicaid, long-term care insurance, prescription coverage, and low-income assistance. Contact: www.nedoi.com/shiip or (800) 443-9354

National Clearinghouse for Long Term Care Information
http://www.longtermcare.gov/LTC/Main_Site/Paying_LTC/Private_Programs/LTC_Insurance/index.aspx. This section of a website developed by the U.S. Department of Health and Human Services discusses the cost of long-term care, what the costs are across the country, and who pays for long-term care. You can find out how much care costs in your state by clicking on an interactive map.

Center for Medicare Advocacy (CMA) is a national organization that provides education, advocacy and legal assistance to help elders and people with disabilities obtain Medicare and necessary health care. There is a wealth of resources on CMA’s website, including self-help packets for dealing with issues beneficiaries may face. You can also contact the Center with questions. Contact: http://www.medicareadvocacy.org/, (860) 456-7790

Medicare Rights Center (MRC) offers many free resources to help people with Medicare and their caregivers understand their rights and options. In addition to written information and webinars, MRC provides a national phone hotline where individuals can consult with counselors about a wide range of Medicare-related issues. It also runs Medicare Interactive – a website that provides detailed information about the ins and outs of Medicare in an easy to understand manner. Contact: http://www.medicarerights.org/, (800) 333-4114
Home Care/Services

Medicare and Home Health Care
This booklet by the Centers for Medicare and Medicaid Services discusses what home health care is, Medicare coverage, how to choose an agency and how to monitor services.

The Personal Assistance Services (PAS) Center
http://www.pascenter.org/pas_users/index.php
The Personal Assistance Services Center’s website section for PAS users provides a wealth of information for consumers employing their own attendant. Its “Guide to Using PAS” covers a range of topics, including finding, interviewing and hiring an attendant, supervising and communicating with an attendant, and firing an attendant. Other sections of the website provide helpful PAS-related information as well.

The MetLife Aging in Place Workbook: Your Home as a Care Setting
The guide walks you through what to consider if you want to make your home into a care setting. It helps you evaluate your needs; determine whether your home needs modifications to permit you to age in place, identify care resources to assist you, including family and friends and paid services and assess the costs of remaining at home and receiving needed care.

Assisted Living/Group Homes

Thinking of Moving to an Assisted Living Residence?
Written by the New York Long Term Care Community Coalition and the Coalition of the Institutionalized Aged & Disabled. http://www.assisted-living411.org/, (212) 385-0355
Designed for potential residents and their families, this guide helps individuals choose an assisted living community that is right for the resident.

Resident’s Guide for Assisted Living.
Written by the New York Long Term Care community Coalition and the Coalition of the Institutionalized Aged & Disabled. http://www.assisted-living411.org/, (212) 385-0355
This book helps people currently in assisted living determine whether their residence meets their expectations and suggests ways to work with staff and other residents to make it better.

Assisted Living Consumer Alliance ALCA) is a national collaboration of groups and individuals working together to promote consumer safety, choice and rights in assisted living. ALCA provides information for both consumers and advocates, and works collaboratively with government officials and health care professionals to improve assisted living. Contact: http://www.assistedlivingconsumers.org/

Where the Heart Is: Choosing a Group Home. This article discusses what to look for and questions to ask when selecting a group home for persons with developmental disabilities. http://www.ilresources.com/articles/Grouphomecriteria.html
Nursing homes

The National Consumer Voice for Quality Long-Term Care is a national organization that represents the voice of long-term care consumers. The Consumer Voice advocates for public policies that support quality care and quality of life; empowers and educates consumers to advocate for themselves; trains and supports individuals and groups that empower and advocate for consumers; and promotes the critical role of direct-care workers and best practices in quality-care delivery. The Consumer Voice connects consumers to a wide range of resources including factsheets, guides, resident council materials and more. Among its publications is “Nursing Homes: Getting Good Care There” by Sarah Greene Burger, Virginia Fraser, Sara Hunt, and Barbara Frank, 2nd edition, 2002. Contact: http://www.theconsumervoice.org/. (202) 332-2275

Advancing Excellence in America’s Nursing Homes is a national campaign to improve quality of care and quality of life for the country’s nursing home residents. It works to achieve this goal by helping nursing homes improve quality in eight key areas; supporting certified nursing assistants and promoting communication between residents, families and nursing home staff. Advancing Excellence provides consumer factsheets and other materials for consumers on its website www.nhqualitycampaign.org

A Baby Boomer’s Guide to Nursing Home Care. This 2006 guidebook by Eric M. Carlson and Katharine Bau Hsiao of the National Senior Citizens Law Center takes a “nuts and bolts” approach to explaining the laws that protect nursing home residents and providing practical advice on how residents and their families can obtain the best nursing home care possible. To order, go to: http://www.nsclc.org/publications/manuals/manual.2006-08-08.4847024259

Appendix 2: Sample Letter Requesting Housing Modification

Date

Dear Ms. Housing/Facility Manager:

I am writing to request a reasonable accommodation/modification with regard to my disability, *describe disability here*, which substantially limits one or more of my major life activities.

Specifically, I am writing to request: *describe the specific change in rule, policy, practice or service, or physical premises, you are seeking.*

I need this accommodation so that I can live here as easily and successfully as the other residents and fully use and enjoy the premises.

I have attached a letter from my doctor certifying that this request is necessary. *(attaching such a letter may or may not be necessary)*

As you probably know, because I have a disability, fair housing laws entitle me to reasonable accommodations/modifications.

Please respond to my request in writing within seven business days. Thank you for your assistance.

Sincerely,

Your Name
Appendix 3: Self-Direction - Is it Right for You?
Adapted from “Mi Via: Is It Right For You,” with permission from the New Mexico Aging & Long-Term Services Department.

Pros and Cons

This worksheet can help you figure out if self-direction is right for you. In the column labeled “Pros,” write out all the reasons self-direction would be right for you. In the column labeled “Cons,” list all the reasons self-direction would not be right for you. After you have listed all the pros and cons, ask your family and friends what they think. They may have ideas that you didn’t think of. List their suggestions in the pros and cons columns too. After you have listed all the pros and cons, decide how important each is to you and rank it according to:

Not important = 1 It matters = 2 Very important = 3

When you are done, every pro and every con should be ranked with a 1, 2 or 3.

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After reviewing all this information, self-direction is:

_____ Right for me

_____ Not right for me

_____ Still not sure
APPENDIX 4: Guidelines for Presenting a Problem
Adapted from The PHI Coaching ApproachSM to Supervision, with permission of the Paraprofessional Healthcare Institute, 2010. (www.PHInational.org)

GUIDELINES FOR PRESENTING THE PROBLEM

1. Describe the behavior—don’t pass judgment on it. For instance, rather than saying, “no one seems to be able to take the time to help,” say, “The last two times I have visited I have found my mother’s call bell going off and her needing to go to the bathroom. Can you tell me what is going on for this to be happening?”

2. Be specific rather than vague. For instance, rather than saying, “It has been like this all week,” say, “The last two times I have visited.”

3. Describe what you observed rather than what you assume to be the reason it happened. Focus on what happened rather than why you think it happened. For instance, don’t assume understaffing. Offer an explanation only if you know for certain it is true.

4. Focus on a behavior rather than the person. For instance, rather than saying, “I am beginning to think no one really cares here,” say, “Normally when I visit my Mom after work she is very comfortable and her needs are met. The last two times I visited her I have found her with the call bell going off and needing to go to the bathroom.”

5. Don’t avoid presenting the problem. Be sure to address the problem behavior or situation even if the immediate situation is resolved.
THREE RULES FOR PRESENTING THE PROBLEM

1. Be clear and direct about what the problem is.

2. Use objective language free from blame or judgment.

3. Indicate belief in the person’s ability to resolve the problem.
APPENDIX 5: Coaching Approach to Communication
Used with permission of the Paraprofessional Healthcare Institute, 2010. (www.PHInational.org)

PHI Coaching Approach® to Communication

Create a Relationship with the Other Person
• Identify any of your own personal emotional triggers or listening blocks; use a pull-back strategy that works for you
• Find a good time to raise the issue
  Private setting
  Careful timing
  Distractions minimized
• Indicate interest and belief in the other person
  Keep an open mind about the person
  Keep an interest in the person, in understanding his or her reality
• Use an inviting and encouraging tone of voice

Present the Problem
• Be clear and direct about what the problem is
• Limit the statement to a single problem (not a litany)
• Use objective language free of blame or judgment
• Emphasize your wish to resolve the problem positively
• Indicate your belief in the person’s abilities, including his or her ability to resolve problems
• Reinforce the positive by pointing out the person’s specific accomplishments and successes

Listen for the Other Person’s Perspective
• Put aside your own agenda while listening
• Listen actively to understand the person’s perspective
• Acknowledge the person’s perspective
• Paraphrase and use open-ended clarifying questions
Resolve the Problem with the Other Person

- Maintain a focus on issue-related behaviors
- Reach mutual agreement on the nature of the problem
- Develop strategies together to address the problem

Obtain Commitment to Action Steps

- Make mutual commitments for specific, measurable action steps
- Follow through on commitments