

Quality Long-Term Care in North Carolina

A Consumer Guide to Choices and Advocacy



**Produced by
Friends of Residents in Long-Term Care**

883-C Washington Street
Raleigh, North Carolina 27605
Telephone: 919-782-1530
Fax: 919-782-1558
Email: friends@forltc.org
Website: www.FORLTC.org

ACKNOWLEDGMENTS

The National Consumer Voice for Quality Long Term Care



This guide was produced by Friends of Residents in Long Term Care. We are grateful to the National Consumer Voice for Quality Long Term Care for providing support to this effort with a grant to Friends of Residents in Long Term Care for the development and initial dissemination. This guide is part of a project led by the National Consumer Voice for Quality Long-Term Care, and funded by the Milbank Foundation for Rehabilitation. The purpose of the project is to empower people with disabilities and older adults to be self-advocates for quality long-term care, while strengthening long-term care citizen advocacy groups that work on behalf of long-term care consumers

The content of this document draws heavily upon a national guide developed by Consumer Voice. For more information about this guide you may visit:

<http://www.theconsumervoice.org/piecing-together-quality-long-term-care>

We especially wish to express appreciation to staff at Consumer Voice, especially **Robyn Grant**, project director for the national guide, and **Jessica Brill Ortiz**, project director for the state guides for their guidance and support throughout the project.

Content and production of the North Carolina Guide was largely the work of **Ana King**, with assistance from project director **Bob Konrad**, and editorial assistance from **Marian Hartman** and **Hank Maiden**.

The work was overseen by a group of consumers and advocates who constituted the project advisory committee and volunteered time to help with the development and implementation of this project. This committee included: **Marian Hartman, Bill Lamb, Sandra Farmer, Sharon Wilder, Annaliese Dolph, Diane Robinson, Trish Farnham, and Ellen Russell**.

Friends also gratefully acknowledge the contributions of Barb Langston for administrative support.

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 facilities. 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 residential care in North Carolina

Table of Contents

Introduction	
Chapter 1: What are “Long-Term Services and Supports?”	5
Chapter 2: Independence Plus Support	6
Chapter 3: Affordable Housing	7
Chapter 4: Housing Rights	9
Chapter 5: Long-term Services and Supports in Residential Settings: When 24-Hour Nursing Supervision/Care is NOT Needed	12
Chapter 6: Long-Term Care, Services and Supports in Residential Settings: When 24-Hour Nursing Supervision/care IS Needed	15
Chapter 7: Hospice	17
Chapter 8: Getting started: Finding Information, Determining Needs and Obtaining Services	18
Chapter 9: Costs & Payment	19
Chapter 10: Financial and Health Care Planning	28
Chapter 11: Advocating for Quality Long-Term Services and Supports: Selecting Your Provider	30
Chapter 12: Advocating for Quality Long-Term Services and Supports: Being Proactive	33
Chapter 13: Advocating for Quality Long-Term Services and Supports: Addressing Problems	38
Chapter 14: Nursing Home Transition	45
Chapter 15: Helping Family and Other Caregivers	50
Chapter 16: Advocating for Quality Care: Improving the Long-Term System	51
Resources	
Appendix 1: List of Resources	
Appendix 2: Description of Waiver services and supports	
Appendix 3: Sample letter requesting housing modification	
Appendix 4: Self-Direction - Is it Right for You?	
Appendix 5: Guidelines for Presenting a Problem	
Appendix 6: Coaching Approach to Communication	

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 that 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.

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, and even finding information, can be difficult. So this Guide is designed to educate and empower you, the consumer, to advocate on your own behalf for the right kind of long-term services and supports at the right time and with the right provider so you have independence, choice, dignity, quality of life and quality care and services. The 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, whereby you communicate your wishes regarding your healthcare to someone you trust and 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 10.

But first, let’s find out more about *Long-term Services and Supports*.

CHAPTER 1: *What are “Long-term services & supports?”*

Long-term services and supports integrate health care treatment and assistance with daily life tasks to address social, environmental, medical, and financial needs over a prolonged period and help you live as independently as possible.

Health Care Treatment - periodic nursing, therapies, medical appointments, medication administration

Activities of daily living” (ADL) - bathing, dressing, eating, toileting/maintaining continence (getting to/from and on/off the toilet), performing personal hygiene, and controlling bowel/bladder functions), getting around (sometimes referred to as “mobility”) and getting in or out of bed or a chair/wheelchair (called “transferring”).

Instrumental activities of daily living (IADL) – housekeeping, meal preparation/cleanup, shopping, accessing transportation, running errands, using the telephone/computer, and banking/managing money.

Long-term services and supports should be person-directed or person-centered. Person-directed care and services focus on your strengths and preferences and put you in charge of determining the direction of your life. It gives you the opportunity to express choice and make decisions in meaningful ways at every level of daily life.¹ Person-directed planning is the process of creating a plan that allows you to build or continue the kind of life you want, with the supports you need to do so. This means you are the one directing or guiding the services you receive, 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

Long-term services and supports are the assistance people need to carry out the tasks of daily living and live as independently as possible

¹ <http://www.pioneernetwork.net/CultureChange/>

² <http://www.pioneernetwork.net/CultureChange/Whatis/>

CHAPTER 2: Independence Plus Support

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 consumers to remain in their own homes and continue to enjoy their independence plus support. 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 will be described in Chapter 9: Costs and Payment. A list and description of many of the services available can be found in Appendix 2.

A good internet resource can be found here:

http://www.longtermcare.gov/LTC/Main_Site/links.aspx

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

1. provide you with information
2. manage your care
3. insure your safety
4. assist you with activities of daily living/instrumental activities of daily living
5. teach you new skills or adaptations
6. help you maintain good physical and mental health
7. modify your home and/or your vehicle to make them accessible
8. keep you integrated into community life
9. provide you with the supplies/equipment you need to live in the community
10. offer therapies that restore or improve your speech, mobility, cognition, behavior, capacity to engage in daily activities
11. train you, your family, and your caregivers
12. provide transportation to appointments

Try to educate yourself about long-term services and supports BEFORE you need them. This will allow you to make more informed decisions with less stress when the time comes.

CHAPTER 3: Affordable Housing Options

Sometimes you may need or choose to find an option other than remaining in your current home that still allows you to maintain your independence. Your current home may have become too difficult to maintain, not be accessible* enough or be priced outside of your comfort zone.

Below are descriptions of some of the more common housing options that are affordable for senior adults or adults with disabilities. Affordable housing is housing for which a person does not have to pay more than 30 per cent of his or her monthly income for rent and utilities.

Subsidized housing is housing that is made available to older adults, persons with disabilities and families who are low-income. Federal subsidized housing is provided through the Department of Housing and Urban Development (HUD). It includes:

- *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. 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> or call the Public and Indian Housing (PIH) Customer Service Center at (800) 955-2232 and request information.
- *Housing Choice Vouchers*- are 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> 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.

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, personal care, bathing, getting to and using the toilet, housekeeping, chore assistance, 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.

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

Accessible housing allows people to do what they want or need to do as independently as possible. Whether or not housing is accessible depends on the type of disability. For instance, access for wheelchair users may mean wider doorways, while it may mean a strobe light smoke alarm in an apartment for someone with a hearing impairment. It is often possible to adapt or modify housing to make it accessible.³

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 onsite, 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.

The best places to start when looking for any housing options are your local Area Agency on Aging, Center for Independent Living or Community Resource Connection for Aging and Disabilities (CRC). The Division of Mental Health/Developmental Disabilities/Substance Abuse Services (DMH/DD/SAS) has a Housing Specialist who interfaces with agencies that specialize in affordable housing. Also, Local Management Entities of the DMH/DD/SAS system each have a Housing Specialist.

³ Informed Consumer's Guide to Accessible Housing

CHAPTER 4: Housing Rights

Your 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 as well.

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

Overcoming barriers to obtaining affordable, accessible housing

Unfortunately, you may face some barriers in obtaining housing that is both accessible and affordable. Here are some common barriers and what you can do to overcome those obstacles.

⁴ <http://www.hud.gov/offices/fheo/FHLaws/yourrights.cfm>

Barrier #1: Shortage of this type of housing. 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 available. 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 or how to find it.

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

To file a complaint online (simple form), go here:

<http://www.hud.gov/offices/fheo/online-complaint.cfm>.

You can file on your own or with help from a lawyer. Free legal assistance may be available from your local legal aid office/legal services provider (contact your Area Agency on Aging, Center for Independent Living or CRC for information). 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.

As a tenant, you have rights that protect you against discrimination. You can request a reasonable modification to your home if it is necessary for you to use the housing. If you feel that your rights have been violated, you can file a complaint with the Office of Fair Housing and Equal Opportunity

CHAPTER 5: Long-Term Services and Supports in Residential Settings: When 24-hour Nursing Supervision/Care is NOT Needed

The time may come when you prefer or it seems in your best interest to move into a residential facility that offers 24-hour care and more opportunities for socialization. In North Carolina, facilities that provide 24-hour residential care and supervision to 2 or more aged and disabled adults and those with mental illness, developmental disabilities including traumatic brain injury, or substance abuse disorders are licensed and regulated by the N.C. Division of Health Service Regulation. When round-the-clock nursing care is not needed but supervision and support services are required, the following residential options are available to those persons who meet eligibility criteria:

According to North Carolina General Statute 131-D, **Assisted Living Facilities** provide 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.

Within this category are two options:

Option #1 – Adult Care Homes. Seven or more Aged or Disabled Adults who require 24-hour supervision and/or assistance with personal care needs live in a group residence where there is a common dining area and common areas for social and recreational activities. Staff is hired to provide personal care and supervision and health care service coordination (medication administration, scheduling appointments, and providing transportation to medical appointments). 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. This unit is usually housed in a secure part of the facility and has a care and activities program specifically designed for persons with dementia. *Adult care homes differ from nursing homes in the level of care and qualifications of staff.* They may provide occasional nursing care as needed but they do not provide 24-hour skilled nursing care.

Option #2 – Family Care Homes. Six or fewer individuals live in the home of an unrelated family or individual homeowner. These homes provide many of the same basic services provided in Adult Care Homes.

For a complete list of Assisted Living Facilities in N.C., go to

www.ncdhhs.gov/dhsr

Click on “Licensed Facilities” and then click on the pdf documents for Adult Care Homes or Family Care Homes.

Local Departments of Social Services assist older and disabled adults with admission to Assisted Living facilities. The DSS in the county in which the home is located is responsible for monitoring provision of services on at least a quarterly basis. In order to secure placement in an Assisted Living facility, *your doctor must complete an FL-2 medical form confirming that you need that level of care.* These forms are available at your local Department of Social Services.

Contact information for Departments of Social Services across the State can be found at www.ncdhhs.gov/dss/local

There is a third category of Assisted Living which is not licensed and for which residents do not require 24-hour supervision. This option is known as **Multi-Unit Housing with Services**. Individuals typically live in their own apartment within a multi-unit complex with protective oversight. If personal care or nursing services are needed by any of the residents, these services **MUST** be provided by a licensed home health or hospice agency.

While there is nothing prohibiting persons with developmental disabilities, traumatic brain injury, mental illness, or substance abuse disorders from living in Assisted Living facilities (in fact, NC has one Assisted Living facility designated specifically for persons with brain injury), there are other residential facilities licensed under G.S. 122-C which are tailored to meet their unique needs. These are collectively called Supervised Living facilities.

Supervised Living Facilities provide 24-hour residential services to two or more adults in a home environment where the primary purpose of services is the care, habilitation, or rehabilitation of individuals who have a mental illness, developmental disability, traumatic brain injury, or substance abuse disorder, and who require supervision when in residence.

Option #1 – Alternative Family Living Individuals live in the home of an unrelated homeowner who provides services and supports.

Option #2 – Supported Living Individuals live in an apartment or house with at least one other resident and receive staff support based on individual needs.

Option #3 – Group Homes Individuals live in a group home for 2 to 6 persons. There is an emphasis on learning self-care and daily living skills. Residents usually participate in day habilitation programs in the community. Programs are adjusted to meet the needs of the target population.

Option #4 – ICF/MR-DD. Individuals with significant developmental disabilities and habilitation needs requiring additional staff support may live in a group home certified as an ICF/MR Facility and are eligible to receive state/federal Medicaid funding.

For a complete listing of all licensed MH/DD/SAS facilities organized by county, go to www.ncdhhs.gov/dhsr. Click on “Licensed Facilities” and then MH facilities or ICF/MR-DD. The type of facility will be identified under the name of each facility.

Local Management Entities of the Mental Health, Developmental Disabilities, and Substance Abuse Services system assist persons with admission to these facilities and monitor the provision of services. Your doctor must complete an MR-2 medical form determining the level of care appropriate for you.

Contact information for the State’s 23 Local Management Entities can be found at www.ncdhhs.gov/mhddsas/lmedirectory.htm

CHAPTER 6: Long-Term Services and Supports in Residential Settings: When 24-Hour Nursing Supervision/Care IS Needed C

Nursing Homes are licensed by the Division of Health Service Regulation. 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.

Nursing Homes provide services and supports to people who need round-the-clock nursing care or supervision. They provide a standard set of core services that include: room and board, personal care, nursing services, dietary services, social services, activities, housekeeping and maintenance. 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.

For a complete list of nursing homes in your area go to www.ncdhhs.gov/dhsr 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 to learn how the quality of each facility is rated using a five-star rating system. Health inspection results, quality measures, and staffing are components of the rating system.

Continuing Care Retirement Communities

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. A complete listing of CCRCs can be found at www.ncdoi.com/fed/se/documents/ccrc/ccrclist.pdf. A profile of each CCRC can be found at www.ncdoi.com/consumerpublications. Any questions about CCRCs may be directed to the Dept. of Insurance at (919) 807-6612.

Developmental Centers are state-operated ICF/MR-DD certified facilities which are eligible to receive state/federal Medicaid dollars. The centers provide 24-hour supervision, care, and training to individuals with significant cognitive limitations. Persons remaining in Developmental Centers are those for whom no appropriate community placement has been identified.

CHAPTER 7: 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 to be 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. These include:

- 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
Or call the Hospice Directory at (800) 854-3402.**

Chapter 8: Getting Started: Finding Information, Determining Needs and Obtaining Services

Where do you find information and resources about long-term care?

You can obtain information 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.

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

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/> or call (877) 525-3400.

Community Resource Connections for Aging and Disabilities (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> 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.

The 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 you figure out what care, services and supports you 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. A number of professionals conduct these assessments. They include:

- 1) Care managers* located through the AAA or a local aging program.
- 2) Care managers or other professionals at the Local Management Entity (for persons with mental illness, developmental disabilities, or substance abuse disorders)
- 3) Care managers through social service organizations in the community (e.g. Catholic Social Services, Family Services Association, Jewish Family and Children Services)
- 4) 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. Many geriatric care managers also work with younger persons with disabilities. To find out more about private care managers, visit: www.caremanager.org.

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

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 the **Resources** section under “Assessment Tools.”

What is self-direction/self-determination, and how do you know if it is right for you?

Decide whether you want to be in charge of your own services and supports. This is called “self-direction” or self-determination and gives you control and flexibility as well as responsibility and duties. If you are eligible for Medicaid Waiver services, (see Chapter 9) 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 and supervise your

attendants, but responsibility for wages, payroll taxes, and worker's compensation insurance is the responsibility of a third-party fiscal intermediary. Here are some points to think about as you consider the option of self-direction⁵:

- You can pick the worker who is most compatible with you and your situation.
- You have more flexibility in scheduling.
- You are responsible for hiring, training and scheduling workers and finding replacements to cover illness and other time off.
- You are responsible for paying workers with the assistance of a fiscal intermediary or public authority.

Appendix 4 offers a worksheet to help you determine if self-direction is right for you.

⁵*Help At Home*, published by the Ohio Department of Aging.

CHAPTER 9: Costs & 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.⁶ These are only averages, costs of some services may be higher in some parts of the state especially in Charlotte or in the Raleigh Durham area.

Home care

Home health aide (from licensed agencies)..... **\$18 per hour**

Homemaker/companion services **\$16 per hour**
(from an agency)

Note: This is the amount you pay the agency. It is not the amount the home health aide or homemaker/companion receives.

Attendant (national figures).....**\$8.91 – 11.99⁷ per hour**

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, with usually at least two meals a day, housekeeping and personal care assistance for a one-bedroom apartment or private room with private bath.

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 year**

National Averages for Alzheimers units are:

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**

You can find out how much care/services cost in other states by going to:

http://www.longtermcare.gov/LTC/Main_Site/Paying_LTC/Costs_Of_Care/Costs_Of_Care.aspx and clicking on a particular state

⁶ <http://www.metlife.com/assets/cao/mmi/publications/studies/2010/mmi-2010-market-survey-long-term-care-costs.pdf>

⁷ [http://www.payscale.com/research/US/Job=Personal_Care_Attendant_\(PCA\)/Hourly_Rate](http://www.payscale.com/research/US/Job=Personal_Care_Attendant_(PCA)/Hourly_Rate)

How do I pay for long-term care?

There are a variety of ways to pay for long-term services and supports. Your options will depend upon your situation. Some payment options require you to meet certain physical and/or financial qualifications. Below is a brief description of the range of payment options.

Medicare

Medicare is a federally-funded and administered 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.

Medicare covers:

1) Home health care, if your care is considered “medically necessary,” and you need skilled nursing care (part-time or from time-to-time) and/or therapies (physical, occupational, speech/language therapy). Medicare home health care also includes home health aide services, medical supplies and durable medical equipment. Medicare will continue to pay for home health care as long as it is determined to be medically necessary; your doctor orders the care every 60 days; your care is provided by a Medicare-certified agency and you are “homebound.” Being homebound means that leaving home is a major effort, and you are unable to leave without personal assistance or the help of a wheelchair, crutches, etc. If you do leave home, it must be to get medical care, or for short, infrequent non-medical reasons such as a trip to get a haircut or to attend religious services.

Beware--*Medicare will not pay for home health aide services if that is all you need. You must also require skilled nursing care and/or therapies to qualify for coverage.*

2) *Skilled nursing home care if you have had a hospital stay of at least three days; you receive care from a Medicare-certified nursing home and you need skilled nursing care and/or therapies. See the section “**Problems with care/services being reduced, terminated or not paid for**” to learn about important information relating to the three-day stay requirement.*

Beware. *Medicare covers very little nursing home care! 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 coverage ends when you no longer need skilled nursing care or therapy. Often a nursing home decides that in its opinion you don't qualify any longer and will notify you that it is stopping services. This decision is frequently based on the incorrect belief that a person does not qualify 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 section “**Problems with care/services being reduced, terminated or not paid for.**”

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

Beware--*Hospice care under Medicare does not pay for room and board if you are in a 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.*

Medicare Part C, known as **Medicare Advantage**, is an option to original Medicare in which private insurance companies receive money from Medicare to provide coverage. Medicare Advantage is required to cover everything included in original Medicare Part A and Part B except hospice care. However, plans vary in terms of out-of-pocket costs, how you get services and extra benefits.

Medigap. Medigap is private insurance that pays for gaps in Medicare coverage like deductibles and co-insurance. It 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.

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. The federal government requires that certain services be provided. Each state determines which additional services it chooses to provide.

You can apply for Medicaid at your local Department of Social Services and learn more about NC Medicaid and services provided from the Division of Medical Assistance website at www.ncdhhs.gov/dma/medicaid.

Medicaid Covers:

- 1) Nursing home services
- 2) Home and community-based services

There are different ways Medicaid pays for services at home or in the community. Here are just a few examples of the various programs:

Medicaid Home Health Services. State Medicaid programs provide home health services that are very similar to the Medicare services described above. However, the federal government has made clear that Medicaid home health programs have less restrictive eligibility requirements than Medicare home health services. For example, Medicaid programs cannot require beneficiaries to be homebound to qualify for home health care.

Medicaid Personal Care Services State Plan Benefit . A Medicaid personal care program will pay to provide assistance with activities of daily living and instrumental activities of daily living to an individual. Individuals must need help with personal care as defined by the state and meet the Medicaid financial requirements.

Medicaid Waiver. 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 persons with Mental Retardation/Developmental 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.

To qualify for Medicaid Waiver services a person must meet:

- a) Financial requirements. The financial eligibility requirements for Medicaid Waivers are different from the requirements for traditional Medicaid. Waivers allow you to have more money and still qualify. Individuals who would not financially qualify for traditional Medicaid may be eligible for waivers.
- b) Level of care requirements. You must need the same level of care as those who qualify for a nursing facility or ICF/MR-DD facility.

These Medicaid Waivers in North Carolina are designed for adults with chronic health conditions or disabilities as follows:

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.

Community Alternatives Program – Choice/Independence Plus (CAP-Choice/IP) This 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.

Community Alternatives Program for Persons with Mental Retardation or Other Developmental Disabilities (CAP/MR-DD) – Comprehensive. This program is for persons with MR/DD who, without these services/supports would have to live in an Intermediate Care Facility for persons with Mental Retardation or other Developmental Disabilities (ICF/MR-DD). 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.

Community Alternatives Program for Persons with Mental Retardation or Other Developmental Disabilities (CAP/MR-DD) – Supports. This program has the same requirements and array of services as the Comprehensive Waiver but is designed for consumers with fewer or lower cost needs and has an annual cost limit of \$17,500 per person.

A listing of the services offered under each waiver along with service descriptions can be found in Appendix 2.

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").

State/County Special Assistance. This benefit is available to low income individuals in group care facilities **other than** nursing facilities and ICF/MR-DD 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 has a limited number of "slots" in 91 counties for individuals who qualify for Assisted Living but want to remain at home and need financial assistance with rent, food, other basic operating expenses. You must be Medicaid eligible.

Older Americans Act The Older Americans Act (OAA) is a federal law authorizing a wide range of services and programs to older adults and their families. The OAA

provides funding through state and local agencies, such as the State Unit on Aging and the Area Agencies on Aging, for a number of home and community-based services. While there are no specific financial eligibility criteria for Older Americans Act services, they are generally targeted for low-income, frail seniors over age 60 and minority elders and seniors living in rural areas.⁸

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 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.

For more information, go to [eBenefits](#), a one-stop shop for benefits-related online tools and information. 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. You can also get information from the National Hotline for VA benefits at 1(800) 827-1000.

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."

CLASS Act. The CLASS (Community Living Assistance Services and Supports) Act creates a new national long-term care insurance program beginning in 2013. Full and part-time workers will be able to choose to have the premiums deducted from their paychecks. After you have participated in CLASS for at least five years and can no longer perform basic activities of daily living, or if you have Alzheimer's disease or other

⁸ http://www.longtermcare.gov/LTC/Main_Site/Paying_LTC/Public_Programs/Public_Programs.aspx

forms of dementia, you will be eligible to receive a daily cash benefit. You will be able to use this benefit to pay for anything that will help you stay at home.⁹

Find out more when it becomes available by going to <http://aoa.gov/AoARoot/CLASS/index.aspx>.

There is not much at this site now, but keep checking back for new information.

Private pay. You pay for services out of your own pocket.

There are two resources listed below that can help you figure out what programs may help you pay for your long-term care services.

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.

State Health Insurance Assistance Program (SHIP):

<http://www.healthassistancepartnership.org/ship-locator/>, 800-MEDICARE

The State Health Insurance Assistance 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. Each state has a SHIP program. In North Carolina, the program is known as the Seniors Health Insurance Information Program (SHIIP) and falls under the NC Department of Insurance. Contact 1-800-443-9354.

⁹ National Council on Aging. Straight Talk for Seniors.
<http://www.ncoa.org/assets/files/pdf/Straight-Talk-for-Seniors.pdf>

CHAPTER 10: Financial and Health Care Planning

While we don't like to think about a time when we can't make our own decisions, 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.

This section provides a very brief and general description of the ways you can express your wishes and give someone the legal authority to make decisions for you.

Financial decisions

Financial Durable Power of Attorney: This is a document in which you can give another person (the agent or attorney in fact) the authority to handle a part or all of your financial matters. To create such a document, a person must be considered to have "capacity" – that is, to be able to understand the nature of the document and to make the decision to have someone else take care of his or her finances. In many states, unless stated otherwise, the financial power of attorney is durable, meaning that it remains in effect if you are no longer able to make your own informed decisions. You can include instructions, guidelines or limitations as you wish. Be cautious: Even though your agent must follow certain legal rules as a "fiduciary," there is no formal oversight of the agent. If there is no one you trust fully to act as your agent, this is not a good tool for you.

Health care decisions

An advance directive is a legal document you can use to plan for your health care needs. In an advance directive, you can: 1) give direction about the type of care and treatment you would want if you can't communicate your wishes and/or 2) appoint someone to make those decisions on your behalf. You must have decision-making capacity to create an advance directive. Persons with disabilities can generally make decisions with the assistance of family, advocates, or agency support personnel. Some individuals with significant cognitive disabilities will lack decision-making capacity, however.

What are the different types of advance directives?

There are essentially two types of advance directives.

1) Durable power of attorney for healthcare (DPOA): a 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. A DPOA can become active any time a person is unconscious or unable to make healthcare decisions. Other terms used for this type of advance directive include healthcare power of attorney and medical power of attorney. Choosing your agent is important. 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 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.

2) Living will: a document in which you give instruction about medical treatment (usually about life support) if you are not able to speak for yourself. In some states a living will applies only to terminal illness or a permanent vegetative state. Living wills involve decisions about life-prolonging treatments such as ventilators, artificial nutrition and hydration, dialysis and antibiotics. Because a living will applies only in certain circumstances, it is best to appoint an agent under a health care power of attorney.

Individuals with serious progressive or terminal conditions may want to ask their doctor about a POLST form (Physician's Order for Life Sustaining Treatment) that will be effective in any care setting. A POLST form is a brightly colored medical form used to write down orders indicating life-sustaining treatment wishes. Not all states recognize these forms. More about POLST in North Carolina is at the POLST website:

<http://www.ohsu.edu/polst/programs/documents/NCProgramDescription.pdf>

Some states have specific requirements or language for advance directives. To get a copy of *North Carolina's advance directive forms*, go to:

<http://www.caringinfo.org/stateaddownload>

“**Five Wishes**” is a helpful document that meets the legal requirements for an advance directive in North Carolina. You can use *Five Wishes* in North Carolina to express how you want to be treated if you are seriously ill and unable to speak for yourself, using a document that is easy to understand. 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 key to good advance planning is discussing your values, beliefs and wishes with your family, friends, doctor and other caregivers. Don't assume that they know what you want!

CHAPTER 11: Advocating for Quality Long-Term Services and Supports: 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.

Track record of provider

- 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/HHCompare>
 - Nursing Home Compare
<http://www.medicare.gov/NHCompare>

Background checks on individual direct care workers are important.

- 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.
- If your attendant is paid for by a Medicaid Waiver, you may be able to select an individual who has already had a background check and is listed on a state registry.*

Who is served? Don't assume that the provider will serve anyone. Ask if there are any age or other limits 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, and the cost of other services that are offered, but not included. 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.

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?

Accommodation of 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.

Person-directed care. Ask how the provider practices person-directed care. Ask them to tell you how they will learn what is important to you and if/how they will honor your choices and decisions.

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?

Staffing levels. If you are considering a residential option, ask what the staff-to-resident ratio is. The fewer residents a nurse, aide or other staff person has to care for, the better!

Staff qualifications and training. Find out what education, training and experience the provider has with the services you want.

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.

Location. 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.

References . Request at least three references.

Checklists. 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 and gather information. 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.

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.

CHAPTER 12: Advocating for Quality Long-Term Services and Supports: 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 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 in which 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! Depending on your situation, you may have rights relating to several different aspects of your care and services. 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, waiting lists and written notice; 4) rights related to both Medicaid and the Medicaid Waiver; 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 wherever and however you receive care and services. In general, such a plan outlines your goals; your abilities and needs; 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; and who will provide the care and services.

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 will 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 our care/service/support plan¹⁰:

- Inform your provider that you want to be involved in developing or reviewing 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 as well.
- 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 that the plan be changed if it is not working or if your condition changes.

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

¹⁰ Caregiver Digest: A Guide to Indiana Long Term Care Resources. United Senior Action Foundation.

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 and their lives.

- 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.¹¹ Because written documentation can influence the quality, type and amount of services you receive, you should review these records periodically for accuracy.

¹¹ Home and Community-based Services for People with Disabilities: Medicaid Waiver Services Guide. Virginia Board for People with Disabilities.

- **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 "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.

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.

Available in every state:

- Long-term care ombudsman¹²
- Centers for Independent Living
- Protection & Advocacy Services. See section, “Addressing Problems,” for information about this agency.
- Citizen advocacy groups - these are organizations at the local or state level that advocate for quality long-term care. To find out about groups in North Carolina, go to: www.theconsumervoice.org, and click on “Get Help” under “Where to Get Help.”

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.

12

CHAPTER 13: Advocating for Quality Long-Term Services and Supports: Addressing Problems

Problems with quality of care/services

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. While you may be very angry about the problem, you will hurt, rather than help your efforts, if you describe the problem with blaming or threatening 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.¹³

- **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.”

¹³ Working for residents, by working with families. National Long-Term Care Ombudsman Resource Center.

- **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 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 whom 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 even 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.
 - 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
 - the person to whom the administrator/director/manager reports
- Document all conversations. Keep copies of any correspondence you receive.
- 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 in group homes that are small ICF/MRs).

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 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 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.
 - In some states where the long-term care ombudsman program serves in-home services clients or there is an ombudsman for Medicaid Waiver services, you can see if the ombudsman will help connect individuals.
- Advocacy organizations might also be of assistance.

Other avenues to pursue:

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

- **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 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.disabilityrightsnc.org or call 888-268-5535.

- **State agency that oversees/regulates 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 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 is provided in Appendix 6.

What do you do about problems if you hire your own attendant?

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 from PHI mentioned earlier, *Guidelines for Presenting the Problem* and *Coaching-based Communication*.
- Contact your local long-term care ombudsman and ask if the ombudsman program covers in-home services regardless of funding source. Most long-term care ombudsman programs don't cover in-home services, but it is worth checking. However, even if the program does not handle home care complaints, the ombudsmen may be able to give you suggestions or strategies to try.
- 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.

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.

While retaliation can and does exist, here are some points to consider¹⁴:

- 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.
- 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.
- Connect with the long-term care ombudsman, the CIL, 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.

Problems with care/services being reduced, terminated or not paid for. Sometimes the problems consumers face relate to services being cut back, 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." 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, submit required paperwork and may require the state to evaluate whether you continue to be medically eligible for the services you are receiving. 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 this problem 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.

¹⁴ Working for residents with families. National Long-Term Care Ombudsman Resource Center.

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/>. The SHIP program may also be able to help.

CHAPTER 14: Nursing Home Transition

What is “nursing home transition?”

Nursing home transition 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 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 participating states 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 if they so choose. Residents are asked if they are interested in transition, and if they respond yes, a referral is made to the Local Contact Agency(s). This is a single or a collection of local organizations that have been designated by the DHHS Division of Medical Assistance in collaboration with the Division of Health Services Regulation (DHSR) and Office of Long Term Services and Supports (LTS) to be responsible for contacting residents, discussing options, and facilitating interested residents to return to the community. 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.

Whom do you contact if you want to move out of your nursing home?

You can start by telling the social worker in your facility and your local long-term care ombudsman that you would like to move into a home in the community. The phone number for your local ombudsman must be posted in the nursing home. The ombudsman will talk with you about your wishes and make a referral.

What does the nursing home transition process involve?

1) Determining your eligibility and conducting your assessment

The state transition program will decide if you are eligible. If you are told you are not eligible, question why. Ask to see what program requirements you don’t meet. You may be able to get help with eligibility issues from your local legal services office.

Next, an assessment will be conducted by a member of the transition program, often called a nursing home transition coordinator (this individual may also be called a care manager or a service coordinator). The transition coordinator will meet with you in your nursing home and talk with you to learn your strengths, abilities, wishes and needs and will review your medical records. Ask your transition coordinator to review your medical records with you if possible. This helps make sure that the information obtained from the

records is accurate and complete. If it is not possible for you to review your records with the transition coordinator, ask him or her to summarize the review for you.¹⁵

Participate as actively as you can in the assessment process. You can play an important role by providing your transition coordinator with information about what's important to you, your strengths, what assistance/supports you need, and your interests, preferences and priorities.

You can ask any one you like to also be involved in the assessment process such as family members, friends or the ombudsman.

2) Developing your transition plan

The information that was gathered during the assessment process is used in creating your transition plan. The plan needs to cover all aspects of your life. Here are just some of the areas that should be included.¹⁶

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?

It's also necessary to obtain approval for the number of hours of care/service you need. Like 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

¹⁵ ABCs of Nursing Home Transition: An Orientation Manual for *New* Transition Facilitators. Judith Holt, Ph.D., Darrell L. Jones, M.A., Richard E. Petty, M.B.A., Helen Roth, M.A., Heather Christensen, M.S. A Publication of the IL Net National Training and Technical Assistance Program at Independent Living Research Utilization. 2006.

¹⁶ Ibid.

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 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 Appendix 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 go up after you leave the nursing home.
- Setting up a monthly budget.
- Applying for community Medicaid. While you are in the nursing home, you have what is called "institutional" Medicaid. When you move out of the facility, however, your Medicaid doesn't automatically transfer to the community. You

have to apply for the appropriate home and community-based Medicaid program, which changes your Medicaid from institutional to “community.”

- Applying for food stamps, utility assistance or other benefits as needed.

You will also need to fill out change of address forms.

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, your transition coordinator 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.

Implementing the plan

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

Get as involved in carrying out the transition activities as you can such as making the calls, requesting information, asking for applications, conducting research, submitting applications, etc. The more responsibility you take on, the more practice you will get in handling the tasks and activities 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. Go visit or talk to someone who has successfully transitioned out. 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 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.

Post transition

Your 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 15: Helping Family and Other 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 is a wealth of 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 may found in Appendix 1.

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, affordable and 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.
- Preventing assisted living providers from evicting residents on Medicaid when providers withdraw from the Medicaid program or fail to renew their contract.
- 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 may 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, (888) 687-2277, TYY (877) 434-7589. In North Carolina, the contact information is 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, (800) 272-3900, TDD: (866) 403-3073
www.alznc.org Eastern NC Chapter (800) 228-8738
Western NC Chapter (800) 888-6671

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, (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 case management and community living opportunities. The Arc also provides information such as factsheets and publications. Contact: www.thearc.org, (800) 433-5255. The contact information for NC is 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: 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.disabilityrightsncc.org or call (888) 268-5535

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 (888) 411-7571

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.nasuad.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.namfcu.net/states/nc>, (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

The National Consumer Voice for Quality Long-Term Care (Consumer Voice) <http://www.theconsumervoice.org/sites/default/files/advocate/Culture-Change-in-Nursing-Homes.pdf> or (202) 332-2275

This factsheet briefly discusses the principles of culture change, presents some person-directed practices, and gives some examples of culture change.

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.

<http://www.metlife.com/assets/cao/mmi/publications/since-you-care-guides/mmi-becoming-effective-advocate-care.pdf>

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/>

Financial and Health Care Planning

American Bar Association (ABA)

<http://www.abanet.org/>, (800) 285-2221

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>.

Hospice

Medicare Hospice Benefits

Center for Medicare and Medicaid Services

<http://www.medicare.gov/publications/pubs/pdf/02154.pdf>

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/>

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:

http://www.eldercare.gov/Eldercare.NET/Public/Resources/Brochures/docs/Housing_Options_Booklet.pdf.

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>

State Health Insurance Assistance Program (SHIP)

<http://www.healthassistancepartnership.org/ship-locator/> or 800-MEDICARE

The State Health Insurance Assistance 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. Each state has a SHIP program.

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

Residential Options

Home care/services

Medicare and Home Health Care

<http://www.medicare.gov/publications/pubs/pdf/10969.pdf>

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

<http://www.metlife.com/assets/cao/mmi/publications/studies/2010/mmi-aging-place-workbook.pdf>

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

<http://www.ilresources.com/articles/Grouphomecriteria.html>

This article discusses what to look for and questions to ask when selecting a group home for persons with developmental disabilities.

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.theconsumervoic.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

National Senior Citizens Law Center

Eric M. Carlson, Katharine Bau Hsiao. 2006.

This guidebook 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.nslc.org/publications/manuals/manual.2006-08-08.4847024259>

ABCs of Nursing Home Transition: An Orientation Manual for New Transition Facilitators.

Judith Holt, Ph.D., Darrell L. Jones, M.A., Richard E. Petty, M.B.A.,

Helen Roth, M.A., Heather Christensen, M.S. A Publication of the IL Net National Training and Technical Assistance Program at Independent Living Research Utilization. Developed in Collaboration with Utah State University Center for Persons with Disabilities. 2006

Although this book is for facilitators, its information can also help consumers who wish to transition out of a nursing home.

APPENDIX 2
Description of long-term services and supports

Below is a listing of home and community-based waiver services that are currently provided in one or more of the previously mentioned NC waivers along with their service descriptions. Waivers have to be reauthorized periodically giving the administering agency an opportunity to add or remove services.

Type of care/service/support	Description
Adult Day Health	Health and social services delivered in an outpatient setting for 4 or more hours per day on a regular basis
Assistive technology	Products, devices or equipment that enable people to maintain or improve their functional capabilities and achieve greater independence. They may aid mobility, cognition, sensory needs, communication.
Augmentative Communication	Devices necessary when normal speech is non-functional
Behavior Consultation	Training, supervision or assistance in learning how to behave and express emotions in ways that are considered to be “socially appropriate”
Care Advisor	Empowers consumers to direct their own personal assistance needs (Choice Waiver)
Caregiver Training and Education	Training to improve a family caregiver’s ability to care for another. Includes training in use of equipment and treatment regimens
Case/Care Management	Specialists who assess consumer needs, help create a plan for services and supports, and arrange, coordinate, manage and monitor those services
Crisis Services	provides an additional staff person so consumer can continue to participate in programs without interruption
Crisis Respite	a period of structured support for consumers in crisis
Day Supports	assistance with acquisition/retention of skills in a non-residential setting

Durable Medical Equipment	Devices and appliances such as wheelchairs, walkers, hospital beds and lifts that assist a person with a medical need or increase their mobility and independence
Environmental/home modification	Adaptation of an existing home to make it more accessible and/or safer and to help make it easier to get around and do daily activities. Examples of modifications include adding ramps, hand rails, grab bars, lever handles on doors, lifts and wider doors.
Financial Management Services	Assures person-directed funds are managed and distributed as intended (Choice Waiver)
Home Mobility Aids	Equipment that enhances mobility
Home & Community Support	Enables individuals to acquire and maintain skills to function in the community
Home Supports	Meet the habilitation and personal care needs of those who choose to live with and receive supports from family
Individual and Caregiver Training	Training and counseling for participant and family to enhance decision-making capacity
Meal Preparation and Delivery	At least one nutritionally sound meal delivered to an individual's home daily
Medical supplies	Health care materials such as dressings, catheters and diabetic supplies
Nursing Services	Services provided for people with serious medical conditions and complex health care needs that require specific skilled nursing services that cannot be provided by non-nursing personnel. Skilled nursing may be provided in the person's home or other community setting on a regularly scheduled or intermittent need basis. Nursing services are ordered by a physician and are provided by a registered professional nurse or licensed practical nurse under supervision of an RN
Participant Goods and Services –	Equipment and supplies not otherwise

<p>Therapies: physical, occupational, respiratory, speech/language</p>	<p>Physical therapy: assessment, treatment and training to maintain or improve functioning such as strength, muscle tone and mobility.</p> <p>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.</p> <p>Respiratory therapy: Assessment, treatment and management of breathing disorders.</p> <p>Speech/language therapy: Assessment and treatment for speech and language communication disorders and swallowing problems.</p>
<p>Transition Services</p>	<p>Covers one-time expenses not to exceed \$2500 per person to set up a home in the community after transitioning from an institutional setting</p>
<p>Transportation</p>	<p>Transportation that enables access to other waiver services</p>
<p>Vehicle Adaptations</p>	<p>Modifications to a vehicle that allow a person to use it to access the community and remain independent</p>
<p>Vocational – Long-Term Support</p>	<p>Assistance in maintaining a job when Supported Employment services are no longer needed/available</p>
<p>Waiver Supplies</p>	<p>Necessary supplies not included in the State Plan</p>

The above services are by no means the only services available to persons who desire/need long-term services/supports. Diagnostic and treatment services, legal assistance, recovery groups, senior centers, support groups, etc. are all available but paid for by a source other than the current North Carolina Medicaid Waivers.

APPENDIX 3
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 4
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.

Pros	Rank	Cons	Rank

After reviewing all this information, self-direction is:

- _____ Right for me
- _____ Not right for me
- _____ Still not sure

APPENDIX 5

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 6

Coaching Approach to Communication
Used with permission of the
Paraprofessional Healthcare Institute, 2010. (www.PHInational.org)



PHI Coaching ApproachSM 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