

**Petition for Adjustment to Need Determination:  
Adult Care Home Beds for Alzheimer's Special Care Unit Beds in  
Stand-Alone Facilities in Buncombe and Cabarrus Counties**

**1. Petitioner**

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Artis Senior Living (Artis) is a private, family owned company that builds, owns, and operates specialized assisted living residences to serve individuals with Alzheimer's Disease and Related Disorders (ADRD). The assisted living residence (i.e., Adult Care Home—ACH with a Alzheimer's Special Care Unit (SCU) license in North Carolina) is based on a proven model that was first developed approximately 20 years ago and improved upon over the years.

The family owners of Artis were the founders of ManorCare back in the mid 1960s, and were the principal owners and managers of ManorCare up until the late 1990s. The family is now focused on stand-alone assisted living facilities for the ADRD population and currently owns and/or operates facilities that they developed in Maryland, New Jersey, Ohio, and Virginia. The Artis senior management had experience developing and operating a similar facility in NC when with ManorCare in the late 1990s.

Artis' website ([www.artisseniorliving.com](http://www.artisseniorliving.com)) provides additional information about the Company and its mission.

## **2. Statement of Requested Adjustment**

Artis Senior Living respectfully requests the State Health Coordinating Council (SHCC) to adjust the 2017 Proposed State Medical Facilities Plan (MFP) by adding a deficit of 331 ACH beds to Buncombe County and 79 ACH beds to Cabarrus County for the specific purpose of serving individuals with Alzheimer's Disease and Related Disorders (ADRD) in stand-alone, specialized facilities licensed entirely as Alzheimer's SCU beds.

## **3. Reasons for the Proposed Adjustment**

Artis requested Philip Sloane, MD, MPH and Sheryl Zimmerman, PhD with the University of North Carolina at Chapel Hill to complete an up-to-date (July 1, 2016) literature search of research on "Estimating the Population and Health Services Needs of Older Persons with Alzheimer's Disease or a Related Dementia (ADRD)." See Appendix A (referred to as the "UNC Study"). In summary, the parameters resulting from this research were applied to the draft 2017 State MFP population projections for 2020 to estimate the need for Alzheimer's SCU beds in Buncombe and Cabarrus Counties. When compared to the existing and planned inventory of ACH beds and those licensed for SCUs in these two counties, deficits were identified, i.e. 331 SCU beds in Buncombe County and 79 SCU beds in Cabarrus County. An overview of the analysis follows.

The UNC Study recommends that the best approach to estimating Alzheimer's SCU bed need is to first estimate the number of persons with ADRD in selected population age cohorts (that conform with the MFP), and to then estimate the number of persons in mild, moderate, and severe stages of the disease. Then estimates of those needing long-term care (LTC) services (i.e., nursing homes, assisted living, home health, adult day, and hospice services) are determined. Of that cohort, an estimate is made of those needing residential care (i.e., assisted living specialized care or nursing home specialized care), as well as an allocation to break out the need for specialized care in assisted living versus nursing homes.

The estimation parameters (i.e., percentages) recommended in the UNC Study that were drawn from an extensive, up-to-date research literature search and review are applied to both Buncombe and Cabarrus Counties' population projections in Table 1. The UNC Study provides the basis for each of the percentages provided in the Table 1, resulting in an estimate of the need for Alzheimer's SCU beds in ACHs in each of the two counties.

### **Buncombe County Alzheimer's SCU Bed Deficit**

Buncombe County has two ACHs with Alzheimer's SCU beds. One is a 38 bed stand-alone facility. See Table 2. There are a total of 59 licensed Alzheimer's SCU beds in the County, with no pending beds to be licensed. Using the UNC Study methodology, there will be a need for 390 Alzheimer's SCU beds in the County by 2020, resulting in a deficit of 331 Alzheimer's SCU beds in ACHs. The existing Alzheimer's SCU beds in the County are virtually fully occupied at present.

The Draft 2017 State MFP projects a deficit of 23 ACH beds by 2020.

Senator Terry Van Duyn, 49<sup>th</sup>, District provided a letter of support for this petition for Buncombe County (See Appendix B). By virtue of her service on the Health and Human Services and Healthcare Committees of the Senate and her representation of the citizens of Buncombe County, Senator Van Duyn has significant insight into the need in that area.

### **Cabarrus County Alzheimer's SCU Bed Deficit**

Cabarrus County has four ACHs with Alzheimer's SCU beds. One is a 25 bed specialized facility adjacent to a general ACH under the same management. See Table 2. There are a total of 118 licensed Alzheimer's SCU beds in the County, with no pending beds to be licensed. Using the UNC Study methodology, there will be a need for 197 Alzheimer's SCU beds in the County by 2020, resulting in a deficit of 79 Alzheimer's SCU beds in ACHs. The existing Alzheimer's SCU beds in the County are 86 percent occupied at present.

Table 1

Buncombe and Cabarrus County Estimates of Alzheimer's SCU Bed Need

(Based on 2017 Draft MFP 2020 Population Estimates and July 1, 2016 UNC Study Estimates)

	Buncombe County				Cabarrus County							
	Age 65 to 74 (2020)		Age 75 to 84 (2020)		Age 85 + (2020)		Age 65 to 74 (2020)		Age 75 to 84 (2020)		Age 85 + (2020)	
	Percent	Total	Percent	Total	Percent	Total	Percent	Total	Percent	Total	Percent	Total
2020 Population Estimate (2017 Draft MFP)		32,541		16,381		6,654		18,111		8,974		3,021
Persons With ADRD By 2020	3%	976	17%	2,785	34%	2,262	3%	543	17%	1,526	34%	1,027
Mild Disease	40%	390	30%	836	25%	566	40%	217	30%	458	25%	257
Moderate Disease	30%	293	30%	836	30%	679	30%	163	30%	458	30%	308
Severe Disease	30%	293	40%	1,114	45%	1,018	30%	163	40%	610	45%	462
Persons Requiring LTC Services		781		2,368		1,980		435		1,297		899
Mild Disease	50%	195	50%	418	50%	283	50%	109	50%	229	50%	129
Moderate Disease	100%	293	100%	836	100%	679	100%	163	100%	458	100%	308
Severe Disease	100%	293	100%	1,114	100%	1,018	100%	163	100%	610	100%	462
Persons Requiring ACH or NH		157		616		792		88		338		360
Mild Disease	20%	39	26%	109	40%	113	20%	22	26%	60	40%	52
Moderate Disease	20%	59	26%	217	40%	272	20%	33	26%	119	40%	123
Severe Disease	20%	59	26%	290	40%	407	20%	33	26%	159	40%	185
Persons Requiring SCU in ACH (Note 1)		43		155		192		25		85		87
Mild Disease	35%	14	35%	38	35%	40	35%	8	35%	21	35%	18
Moderate Disease	35%	21	35%	76	35%	95	35%	12	35%	42	35%	43
Severe Disease	40% of 35%	8	40% of 35%	41	40% of 35%	57	40% of 35%	5	40% of 35%	22	40% of 35%	26
<b>Total County Need for SCU Beds in ACHs</b>				<b>390</b>						<b>197</b>		

Note 1 -- It is assumed that all mild and moderate disease persons requiring SCU in an ACH or NH are best served in the SCU in an ACH. It is assumed that 60 percent of those with severe disease are best served in a nursing home since many residents have significant other disease comorbidities requiring nursing home care.

**Table 2**

**Inventory of Licensed Alzheimer's Special Care Unit Beds in Buncombe and Cabarrus Counties**

Facility Name (Note 1)	No. ACH Beds	No. SCU Beds	ACH Occupancy (Note 2)	SCU Occupancy (Note 3)
<b>Buncombe County</b>				
Arbor Terrace of Asheville	70	21	86%	94%
Brookdale Asheville Walden Ridge (Stand-alone Facility)	38	38	85%	97%
<b>Total</b>	<b>108</b>	<b>59</b>	<b>86%</b>	<b>96%</b>
<b>Cabarrus County</b>				
Brookdale Concord Parkway (Specialized Facility Adjacent to ACH)	112	25	85%	92%
Brookdale Concord South	60	30	65%	78%
Carillon Assisted Living of Harrisburg	96	24	72%	87%
Morningside of Concord (2nd Fl of ACH)	105	39	88%	79%
<b>Total</b>	<b>373</b>	<b>118</b>	<b>79%</b>	<b>86%</b>

Note 1--Source--DHHS, Division of Health Service Regulation, LTC System, Facilities with Special Care report, 4/15/2016

Note 2--Based on one year utilization data ending 7/31/15 as reported on individual facility license renewal applications

Note 3--Based on mystery shop of Buncombe facilities on 7/8/16 and Cabarrus facilities on 7/14/16

Although the Draft 2017 State MFP projects a surplus of 296 ACH beds by 2020, existing ACH beds would need to be converted to Alzheimer's SCU beds to meet the 79 bed Alzheimer's SCU deficit. Conversion of existing ACH beds is not a desirable alternative for the reasons outlined in Section 3.B. (Alternatives Considered) below.

Representative Linda Johnson, 83<sup>rd</sup> District, also wrote in support of this petition (See Appendix C). Representative Johnson, who represents Cabarrus County, wrote that "[i]ndividuals with Alzheimer's disease and related disorders in Cabarrus County are in urgent need for the appropriate facilities that the adjustment would provide.

### **Validation of Projection Methodology**

For the purpose of validating the projection methodology used, we applied the UNC Study methodology to the two largest counties in North Carolina, Mecklenburg County (2020 projected total population of 1,142,325) and Wake County (2020 projected population of 1,105,190). Arguably these two counties are two of the most sophisticated in LTC service delivery and have reached equilibrium in supply of and demand for Alzheimer's SCUs. The one-day occupancy reported in the license renewal applications for 7/31/15 for Alzheimer's SCU beds averaged 87 percent for Mecklenburg and 86 percent for Wake Counties. Mecklenburg has eight stand-alone Alzheimer's SCU facilities and Wake has three.

For Mecklenburg County, the UNC Study Methodology resulted in a projected need of 879 Alzheimer's SCU beds in 2020 (See Appendix D). The current inventory (including 76 SCU beds pending license—40 Preston House and 36 Carillon AL of Mint Hill) is 808, only 0.5 percent in excess of the projected need. Similarly for Wake County, the projected need is for 877 SCU beds and the inventory is 914, representing only a 4.2 percent excess.

These findings make a strong case for the validity of the projection methodology.

## **A. Adverse Effects if Additional Alzheimer's SCU Beds are Not Built**

As cited in the attached UNC Study, the bulk of persons with ADRD requiring residential placement in either a SCU in a Nursing Home or ACH are being served in the ACH setting. Those persons in the severe stage of the disease with significant other disease comorbidities (e.g., severe chronic lung disease or vascular skin ulcers) or who are dependent in all activities of daily living may be best served in a nursing home environment.

The SCU setting in ACHs has evolved over the past 10 to 20 years as a preferred environment to that of the Nursing Home (NH) environment. The SCU/ACH environment is more homelike and comfortable. Stand-alone, specially designed SCUs, where the entire management and staff are trained and focused on dementia care tend to provide higher attention to the details of serving the ADRD population.

If there is an inadequate supply of SCU beds in ACHs, ADRD persons requiring residential care will be prematurely placed in institutional NH environments. This will not only result in lower quality of life for the residents, but will also result in higher cost placements. The overall cost to the State Medicaid program will be driven up if Medicaid eligible individuals, who could otherwise be served in a SCU of an ACH, are prematurely placed in a NH.

Individuals with ADRD exhibiting behavioral symptoms (e.g., wandering, disruptive behavior, "inappropriate" table manners) not socially acceptable to those elderly who are cognitively alert are not well served when mixed with the general ACH population in a facility. Both the quality of life of individuals with dementia and the quality of life of the alert individuals in the ACH residence are compromised when the two populations are mixed. The overall community and the ACH community is best served when there is an adequate supply of Alzheimer's SCU beds to meet the demand.

## **B. Alternatives Considered and Not Found Feasible**

The only feasible alternative is to convert existing beds licensed as ACH beds to specially licensed Alzheimer's SCU beds. Several facilities have gone through this process over the years. There are three downsides to this approach.

First, the typically alert assisted living resident residing in an ACH may not be best served. A general ACH provides the best environment for the alert resident when it is primarily comprised of non-SCU beds. It is critical to have adequate public areas and access to outdoor space for the general population, and that the programs and activities are geared to the general assisted living population. When the number of secured SCU beds in an ACH are significantly increased, it can negatively impact the complexion of the entire facility for the general assisted living population.

Second, the physical conversion of existing ACH beds to SCU licensing standards in NC is often problematic and results in a less than desirable setting for the ADRD residents. The SCU setting should provide relatively small, residential settings where ADRD persons can live in groups not to exceed typically 16 or so residents in a home-like setting with a living room, dining room and residential kitchen (setting) with, most desirably, private bedrooms. ADRD residents are best served by environments that encourage spending time in public areas facilitating social interaction, as opposed to being sequestered in an assisted living apartment unit alone.

Also, there needs to be adequate space to enjoy programs and activities. The space needs to be secured to allow for "purposeful" wandering by residents, with easy access to secured and inviting outdoor space (preferably on the ground floor). The secured units need to be easily accessed by family visitors at all hours in a respectful setting.

To create the above physical space environment in a converted area of an ACH, that was designed and built as a general assisted living facility with apartment units, can be very challenging, and often results in inadequate environments. Often these conversions result in second floor units with little to no access to outdoor areas, inadequate public



areas and long hallways that are not conducive to “purposeful” wandering by residents. It is not uncommon to see agitated residents “exit seeking” in converted SCUs in assisted living facilities because of the inadequate physical environments.

Third, not only do specially built, stand-alone SCU facilities allow for the design of an appropriate environment for persons with ADRD (e.g., home-like, interesting spaces, shorter hallways, adequate public spaces, access to protected and interesting outdoor environments, and lots of natural light), the entire focus of the management and staff is on serving the ADRD population. All staff are trained and should become skilled at working with persons with ADRD and their families. Families of persons with ADRD typically need substantial support and understanding from the staff. The focus, from the time the family makes the initial call to the facility to inquire about the services throughout the entire stay, is on the potential needs of the individual with ADRD and their families.

It is more difficult for an ACH management and staff with an Alzheimer’s SCU wing to be able to provide the individual attention to and understanding of the individual with ADRD and their families. It is not to say there are not excellent SCU wings of ACHs, especially those that were purpose-built upon the initial construction of the ACH. However, it is the Artis management experience with over 20 years of building and operating both stand-alone facilities and those with special care wings, that the success factors ensuring a quality operation for the ADRD resident and their families is enhanced in a stand-alone facility.

#### **4. Evidence That Proposed Adjustment Would Not Result In Unnecessary Duplication**

The demonstrated need for additional Alzheimer’s SCU beds in the analysis presented above demonstrates that approval of this petition would not result in unnecessary duplication of existing or approved facilities. This conclusion is further validated by the application of the methodology used in this petition to the currently well-served Mecklenburg and Wake Counties.

## **5. Consistency With State MFP Three Basic Principles**

### **Safety and Quality**

Purpose-built Alzheimer's SCUs, particularly in stand-alone facilities, are designed specially to provide a safe environment and to enhance the quality of life for individuals with ADRD. For example, Artis Senior Living builds stand-alone facilities based on a proven model that was first developed approximately 20 years ago and improved upon over the years. The residence is typically single-story with 64 beds and consists of four interconnected "houses" typically serving up to 16 residents each. Each house has a living room, dining room, kitchen and spa and typically 16 bedrooms. The four "houses" are connected to a neighborhood center including the health care center, community center, arts and crafts area, and salon. The entire residence provides "secured freedom" for the residents both inside and outside of the residence, which is surrounded by a secured outdoor area that covers three quarters of the perimeter of the residence.

The total focus of the management and staff of the facility is on serving individuals with ADRD and their families.

The specialized, purpose-built stand-alone facility typically provides a safer environment with a higher quality of life than SCU wings of ACHs, especially those that are converted to SCUs after-the-fact.

### **Access**

Additional Alzheimer's SCU beds will provide greater access to individuals with ADRD who have need for a residential placement in a safe and secure environment. Other than SCUs in ACHs, the only other alternative is a nursing home. The SCU/ACH setting is more desirable and appropriate in most instances than a nursing home. Access to those eligible for Medicaid in the SCU/ACH setting provides an alternative to Medicaid eligible residents who would otherwise end up in a nursing home, often inappropriately, because there is no appropriate space available in an Alzheimer's SCU in an ACH in the local community.

## **Value**

The Alzheimer's SCU of an ACH provides a higher quality of life at a lower cost to individuals with ADRD and their families. The Medicaid reimbursement rate in the SCU is less than that in the NH. Moreover, the private pay rate in the SCU is typically less than the private pay rate in a NH.

# APPENDICES

## **Appendix A**

UNC Study

## **Appendix B**

Buncombe County Letter of Support –  
Senator Terry Van Duyn, 49<sup>th</sup> District

## **Appendix C**

Cabarrus County Letter of Support –  
Representative Linda Johnson, 83<sup>rd</sup> District

## **Appendix D**

Validation of UNC Study Methodology in:

- (1) Mecklenburg County
- (2) Wake County

# **Estimating the Population and Health Services Needs of Older Persons with Alzheimer's disease or a Related Dementia (ADRD)**

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Organizations planning health services to meet the needs of the growing population of persons with Alzheimer's disease and related dementias (ADRD) benefit from population projections on which they can base their plans. This document reviews existing literature on the characteristics of persons with dementia, and provides guidelines for estimating (1) the proportion of persons aged 65 and older with ADRD, by age category (65-74, 75-84, 85 and over); and (2) the need for long-term care services, including residential long-term care, for that population.

Considerable data are available estimating the number and proportion of persons with ADRD in the United States (US), overall and by residence. Figures vary because studies differ in the year they were conducted, the sampling method used, and the strategy employed to identify who did and did not have ADRD. In addition, very few studies sought to categorize the dementia population by severity. Even among nursing home populations, where the amount of published research is greatest, study methods are highly varied and so no consensus exists on the precise number of persons with ADRD or the characteristics of the ADRD population (Palm et al., 2016). In this report, we have attempted to develop the best possible overall population estimates for use in estimating health services needs for older adults with dementia.

### **Alzheimer's Disease and Related Dementias (ADRD): Definition and Nomenclature**

The term dementia describes a group of chronic, progressive brain disorders that develop in adulthood (usually in older age) and gradually rob the individual of the ability to think independently and eventually to control basic bodily functions. Alzheimer's disease is the most common dementia, accounting for approximately 70% of all cases. Vascular dementia accounts for 17% of cases, and other dementias (e.g., dementia, undetermined etiology; Parkinson's dementia; normal pressure hydrocephalus; frontal lobe dementia; alcoholic dementia; traumatic brain injury; Lewy body dementia) account for the remaining 13% (Brookmeyer et al., 2011).

From a health care services perspective, most dementias are associated with relatively similar care needs and requirements, because they lead to progressively more serious impairment of decision-making and other cognitive functions and to gradual reductions in self-care capability, culminating in incapacity and death. Therefore, it is traditional in health services planning to refer to these diseases as a single category, commonly known as Alzheimer's disease and related dementias (ADRD).

### **Prevalence of ADRD in the U.S. Overall, by Age, and by Stage of Disease**

**Prevalence of Alzheimer's disease and related dementias (ADRD) in the United States.** According to the Alzheimer's Association, an estimated 5.4 million Americans currently suffer from ADRD (Alzheimer's Association, 2016). Lower estimates of ADRD prevalence do exist – most notably those of Brookmeyer and colleagues (2011) – but these lower estimates are based on surveys that had large non-respondent rates, and persons with ADRD are precisely those who are least likely to respond to surveys. Further, studies have shown that a large group of persons have undiagnosed ADRD who would be easy to miss in surveys; for example, our own research in assisted living communities found that approximately 45% of residents have a chart-based ADRD diagnosis and an additional 38% of the remainder received an ADRD diagnosis when evaluated by a neurologist and neuropsychologist (Zimmerman et al., 2007).

**Prevalence of ADRD by age.** Of the 5.4 million Americans with ADRD, 5.2 million (96%) are aged 65 and older and only 200,000 (4%) are under age 65. The rate of ADRD among persons 65 and older is as follows (Alzheimer's Association, 2016; Ortman et al., 2014):

- 15% of the ADRD population is aged 65-74; thus, an estimated 780,000 persons with ADRD are in this age group. The US population in 2012 included 23,985,000 persons aged 65-74, yielding an estimated ADRD prevalence of 3% in this age cohort.
- 44% of the ADRD population is aged 75-84; thus, an estimated 2,236,000 persons with ADRD are in this age group. The US population in 2012 included 13,273,000 persons aged 75-85, yielding an estimated ADRD prevalence of 17% in this age cohort.
- 37% of the ADRD population is aged 85 and older; thus, an estimated 1,976,000 persons with ADRD are in this age group. The US population in 2012 included 5,887,000 persons aged 85 and older, yielding an estimated ADRD prevalence of 34% in this age cohort.

**Prevalence of ADRD by stage of the disease.** There are several methods of staging persons with ADRD. The most simple and practical method is to categorize the population into mild (early), moderate (middle), and severe (late) stages, plus a pre-diagnostic phase referred to as mild cognitive impairment (MCI). This classification reflects the Clinical Dementia Rating (CDR) system, which is used by the national consortium of Alzheimer's Disease Research Centers to stage persons with ADRD (Fillenbaum et al., 1996).

- Persons with mild dementia tend to be ambulatory. They frequently need some help with grooming, bathing, and dressing; have impaired memory and decision-making; tend to need help with some household activities, such as managing finances and home maintenance; and often exhibit dementia-related behavioral symptoms, such as repeated questions, mood lability, and wandering. The majority of persons with mild dementia can be cared for in the community with family assistance, home care services, and/or adult day services; those who enter assisted living or nursing home settings tend to do so because they lack family support, have comorbid illness requiring ongoing supervision (such as diabetes or chronic lung disease), or have behavioral symptoms that make in-home caregiving difficult.
- Persons with moderate dementia span a wide range of capabilities and disabilities. They tend to require 24 hours supervision; have increasing problems with verbal communication; require hands-on assistance with personal care activities such as bathing; are at increased risk for falls because of mobility problems; and develop occasional or daily incontinence. Many persons with moderate dementia move into assisted living or nursing home settings because families are unable to provide the degree of supervision and assistance needed.
- Persons with severe dementia tend to need help with most activities of daily living, although the ability to feed and reposition often remains during much of this stage. They tend to say few words; have unstable gait or are unable to walk; and over several years deteriorate to the point where they are no longer able to carry out basic functions, become terminally ill, and die of their disease. The majority of persons with severe dementia spend some time in assisted living or nursing home settings, although a significant minority are maintained at home with family support and community-based services.

The figure below graphically describes some of the features and characteristics of the disease stages.

Selected Signs and Symptoms of AD, by Disease Stage *				
Stage of Dementia	MCI	Mild (Early)	Moderate (Middle)	Severe (Late)
Cognition Impaired	recent memory, planning		most memory & decision-making	
Behavioral Symptoms	wandering			
	irritability, personality changes, aggressiveness, hollering			
Assistance Needed	finances, planning, travel, medications			
	meal preparation, housework			
	bathing/ dressing/ grooming			
			continence/ toileting	
Speech			transfer/ mobility	
				eating
MMSE score	Paragraphs	Sentences	Phrases	Single words or sounds
	> 24	24-18	17-9	8-0

\* Adapted from Sloane, Khandelwal, & Kaufer, 2011  
MCI = mild cognitive impairment; MMSE = mini-mental state examination

Among all persons in the US with ADRD, 27% are estimated to have mild disease, 30% to have moderate disease, and 43% to have severe disease (Alzheimer's Association, 2015). Among persons with ADRD living in community settings (i.e., excluding most nursing home and assisted living residents), the estimated distribution by severity is 48% with mild dementia, 31% with moderate dementia, and 21% with severe dementia (Hebert et al., 2003).

**Estimated age-stratification by disease severity.** Age-stratified estimates of dementia severity are not available; however, since the average time course of ADRD is 8-10 years after diagnosis, it can be assumed that the age group 65-74 includes a higher proportion of mild dementia, and the age group 85+ a higher proportion of persons with advanced disease. Therefore, we have estimated the following proportions based on existing data and the course of the disease:

- among persons aged 65-74 we estimate that approximately 40% have mild disease, 30% have moderate disease, and 30% have severe disease;
- among persons aged 75-84 we estimate that approximately 30% have mild disease, 30% have moderate disease, and 40% have severe disease; and
- among persons aged 85+ we estimate that approximately 25% have mild disease, 30% have moderate disease, and 45% have severe disease.

The number of persons with ADRD is projected to increase in the coming decades, in large measure because of projected increases in life expectancy and in the overall number of older persons in the US. How much the ADRD population is estimated to grow varies widely; on average, however, it is estimated to about double by 2050. New advances in therapy may delay the onset or alter the progression of the disease, thereby changing the overall prevalence and/or the relative distribution of mild, moderate, and severe cases; however, due to growth of the aging



population, the number of persons with ADRD will continue to increase even if new therapies are considerably more successful than current treatment (Sloane et al., 2002).

**Prevalence of behavioral symptoms in persons with ADRD.** Among the most challenging aspects of ADRD care are behavioral symptoms that interfere with socialization and care provision. These symptoms include delusions (30% of persons with ADRD), hallucinations (16%), agitation/aggression (40%), disinhibition (18%), and irritability (34%; Lyketsos et al., 2002). In one study, four symptoms were especially linked to family decisions to place someone with ADRD in residential long-term care: severity (stage) of dementia, physical aggression, hallucinations, and depressive symptoms (Gilley et al., 2004).

### **Health Services Needs of and Use by Persons with ADRD**

**Nursing homes.** As of 2014, US nursing homes had an average census of 1,316,800 residents; the age distribution of residents was 15.1% age <65, 16.1% age 65-74, 27.2% age 75-84, and 41.6% age 85 and older; of all residents, 46%-50.4% had a recorded dementia diagnosis (Harrington et al., 2015; Harris-Kojetin et al., 2016). Many residents have undiagnosed ADRD, however, and the true prevalence of ADRD in nursing homes has been estimated to be 64% (more than 840,000 persons; Gaugler et al., 2014). Of nursing home residents with dementia, 2014 figures from the U.S. Center for Medicare and Medicaid Services identified 36.6% with no or mild cognitive impairment, 24.8% with moderate cognitive impairment, and 38.7% with severe cognitive impairment (CMS, 2016).

**Assisted living communities.** As of 2010 733,000 persons resided in assisted living communities in the US ( Park-Lee et al., 2013). According to a 2014 survey, the age distribution of residents was 7.2% < age 65, 10.4% age 65-74, 29.9% age 75-84, and 52.6% age 85 and older (Harris-Kojetin et al., 2016). Between 39.6% and 42% of assisted living residents have a recorded dementia diagnosis (Harris-Kojetin et al., 2016; Park-Lee et al., 2013). Including persons who lack a specific diagnosis on the medical record, the estimated rate of ADRD is 72% (Zimmerman et al., 2007). In terms of the distribution by disease severity, based on a national sample, 29% had mild, 23% moderate, and 19% severe cognitive impairment (Zimmerman et al., 2014) Behavioral symptoms of dementia such as wandering and refusing to bathe have been identified in between 28% and 38% of assisted living residents (Sloane et al., 2005; Zimmerman et al., 2014).

**Specialized dementia care in nursing homes and assisted living.** Specialized dementia care arose in the 1980s as a means of providing enhanced services to persons with ADRD – particularly those whose care needs were complicated by dementia-related behavioral symptoms (Berg et al., 1991). Initially, these programs arose in nursing homes, and increasingly they are located in assisted living communities. As of 2014, nursing homes had 73,742 dementia special care unit beds, with 0.4% of nursing homes being ADRD-specific, and an additional 14.8% having one or more dementia special care units (Alzheimer's Association, 2016; Harris-Kojetin et al., 2016). Of the 971,900 beds in assisted living communities in the US in 2010, an estimated 13% (more than 125,000 beds) were in dementia special care units (Park-Lee et al., 2013); data from 2014 indicate that 10.1% of assisted living communities exclusively serve persons with dementia, and an additional 12.1% have a dedicated dementia unit (Harris-Kojetin et al., 2016).

**Estimates:** Applying the rates and population figures noted above, we estimate that 842,752 persons with ADRD are in nursing homes and 527,750 are in assisted living. Given 5.4 million persons with dementia, the estimated proportion of persons with ADRD residing in nursing homes and assisted living is 25.6% (1,370,512/5,400,000).

**Non-institutional, community-based care.** An estimated 58% of persons with ADRD live in the community. Of these, 92% receive informal care, primarily from family members. Formal service use, provided by paid caregivers, is also common.

- Home health services are used by 25% of persons with dementia each year, and persons with ADRD comprise 31.4% of the clients served by home health agencies (Alzheimer's Association, 2016; Harris-Kojetin et al., 2016). In addition, many more use a variety of paraprofessional paid caregivers and unlicensed workers.
- Adult day services reach an average of 273,200 users nationally (Dwyer et al., 2014). Of these, between 30% and 32% have ADRD (Alzheimer's Association, 2016; Harris-Kojetin et al., 2016). Adult day services users tend to be younger than other users of long-term care services: 36.4% are <65 years old, 20.0% are aged 65-74, 27.5% are aged 75-84, and 16.2% are age 85 and older (Harris-Kojetin et al., 2016).
- Hospice services are frequently used by persons with ADRD who are at the end of life. ADRD is the primary diagnosis of 61,146 hospice enrollees annually, and an additional 119,872 hospice enrollees have ADRD as a secondary diagnosis. The average length of stay for hospice beneficiaries with ADRD as their primary diagnosis is 106 days (Alzheimer's Association, 2016). Hospice clients tend to be among the oldest users of long-term care services: 5.6% are age <65, 17.1% are aged 65-74, 30.0% are aged 75-84, and 47.3% are aged 85 and older (Harris-Kojetin et al., 2016).

### **Creating Population-Based Estimates of Health Services Needs for Persons with ADRD**

Drawing from the data and estimates provided above, we provide this guide to estimating the dementia care needs of a population.

Creating estimates for persons aged 65-74. If the number of persons is  $N_{65-74}$ , then:

- The estimated number of persons with ADRD is  $0.03(N_{65-74})$
- Of the persons estimated to have ADRD:
  - Approximately 40% will have mild disease, 30% moderate disease, and 30% severe disease.
  - On any given year, approximately half of those with mild disease and all of those with moderate or severe disease will need long-term care services from family and/or formal care services. Among all persons aged 65-74 with ADRD the percentage needing residential long term care (assisted living or nursing home care) will be approximately 20%.<sup>a</sup>
  - Within residential long-term care, the proportion of persons with ADRD who have dementia-related behavioral symptoms significant enough to markedly impact care provision will be between 30% and 40%. These would be the individuals who would be most likely to benefit from dementia-specific programming.

Creating estimates for persons aged 75-84. If the number of persons is  $N_{75-84}$ , then:

- The estimated number of persons with ADRD is  $0.17(N_{65-74})$ .
- Of the persons estimated to have ADRD:
  - Approximately 30% will have mild disease, 30% moderate disease, and 40% severe disease.
  - On any given year, approximately half of those with mild disease and all of those with moderate or severe disease will need long-term care services from family and/or formal care services. Among all persons aged 75-84 with ADRD the percentage needing residential long term care (assisted living or nursing home care) will be approximately 26%.<sup>a</sup>
  - Within residential long-term care, the proportion of persons with ADRD who have dementia-related behavioral symptoms significant enough to markedly impact care provision will be between 30% and 40%. These would be the individuals who would be most likely to benefit from dementia-specific programming.

Creating estimates for persons aged 85 and older. If the number of persons is  $N_{85+}$ , then:

- The estimated number of persons with ADRD is  $0.34(N_{85+})$ .
- Of the persons estimated to have ADRD:
  - Approximately 25% will have mild disease, 30% moderate disease, and 45% severe disease
  - On any given year, approximately half of those with mild disease and all of those with moderate or severe disease will need long-term care services from family and/or formal care services. Among all persons aged 85 and older with ADRD the percentage needing residential long term care (assisted living or nursing home care) will be approximately 40%.<sup>a</sup>
  - Within residential long-term care, the proportion of persons with ADRD who have dementia-related behavioral symptoms significant enough to markedly impact care provision will be between 30% and 40%. These would be the individuals who would be most likely to benefit from dementia-specific programming.

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<sup>a</sup> Within residential long-term care the distribution of beds and services between nursing home and assisted settings displays considerable overlap between the two settings and considerable variation from state-to-state. In general, however, assisted living has emerged in the past 10 years as the setting providing the majority of dementia-specific care settings for persons with mild and moderate dementia, and some persons with severe dementia. Nursing homes tend to be the setting of choice for persons with dementia who have significant other disease comorbidities (such as severe chronic lung disease or vascular skin ulcers) or who are dependent in all activities of daily living.



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HEALTH CARE  
JUDICIARY II  
STATE AND LOCAL GOVERNMENT  
TRANSPORTATION  
WAYS & MEANS

July 19, 2016

Christopher G. Ullrich, M.D., Chair  
North Carolina State Health coordinating Council  
809 Ruggles Drive  
Raleigh, NC 27603

Dear Dr. Ullrich:

I am writing to express my support for the petition submitted by Artis Senior Living, LLC, requesting an adjustment to the need determinations in the proposed 2017 North Carolina State Medical Facilities Plan. The requested adjustment would permit the development of additional adult care home beds to serve individuals with Alzheimer's disease and related disorders in Buncombe County. Having served on the Health and Human Services and Healthcare Committees of the Senate, I am familiar with the urgent need for appropriate facilities to care for persons suffering from dementia across North Carolina.

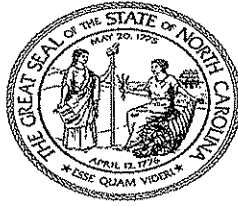
Based upon my review of this petition, I believe the requested adjustment would benefit citizens of the county I represent by both increasing access to high quality care and providing an alternative to more costly skilled nursing facilities. The petition offers evidence to demonstrate that individuals with Alzheimer's disease can often be most appropriately served in stand-alone, specialized facilities licensed entirely as Alzheimer's special care unit beds. I believe that such a facility would be tremendously beneficial in Buncombe County, which is a highly desirable retirement destination. Additionally, development of such facilities in Buncombe County would allow the State Health Planning Agency to evaluate the quality and cost effectiveness of such stand-alone facilities. If this model of care is found to be superior to others available, granting the petition might benefit not only Buncombe County, but also other areas across the State.

Thank you for your work on the State Health Coordinating Council, and your consideration of this petition.

Very truly yours,

Terry Van Duyn  
Senate District 49





NORTH CAROLINA GENERAL ASSEMBLY  
House of Representatives

REPRESENTATIVE LINDA JOHNSON  
83<sup>rd</sup> District  
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July 27, 2016

Christopher G. Ullrich, M.D., Chair  
North Carolina State Health coordinating Council  
809 Ruggles Drive  
Raleigh, NC 27603

Dear Dr. Ullrich:

I am writing to express my support for the petition submitted to request a need adjustment in the proposed 2017 North Carolina State Medical Facilities Plan. Individuals with Alzheimer's disease and related disorders in Cabarrus County are in urgent need for the appropriate facilities that the adjustments would provide. The requested adjustment would benefit citizens by both increasing access to high quality care and providing an alternative to more costly skilled nursing facilities. Such a facility would be immensely beneficial and would allow the State Health Planning Agency to evaluate the quality and cost effectiveness of such stand-alone facilities.

Thank you for your work on the State Health Coordinating Council, and your consideration of the petition.

Sincerely,

Rep. Linda Johnson  
83<sup>rd</sup> District

Estimates of Alzheimer's SCU Bed Need--FOR VALIDATION PURPOSES

(Based on 2017 Draft MFP 2020 Population Estimates and July 1, 2016 UNC Study Estimates)

Mecklenburg County

	Age 65 to 74 (2020)		Age 75 to 84 (2020)		Age 85 + (2020)	
	Percent	Total	Percent	Total	Percent	Total

2020 Population Estimate (2017 Draft MFP)

14562

84376

37082

4951

34%

17%

2531

3%

Persons With ADRD By 2020

1238

25%

30%

1013

40%

Mild Disease

1485

30%

30%

759

30%

Moderate Disease

2228

45%

40%

759

30%

Severe Disease

4332

100%

100%

2025

100%

Persons Requiring LTC Services

619

50%

50%

506

50%

Mild Disease

1485

100%

100%

759

100%

Moderate Disease

2228

100%

100%

759

100%

Severe Disease

1733

40%

26%

405

20%

Persons Requiring ACH or NH

248

40%

26%

101

20%

Mild Disease

594

40%

26%

152

20%

Moderate Disease

891

40%

26%

152

20%

Severe Disease

419

35%

35%

110

40% of 35%

Persons Requiring SCU in ACH (Note 1)

87

35%

35%

35

35%

Mild Disease

208

35%

40% of 35%

53

35%

Moderate Disease

125

40% of 35%

40% of 35%

21

40% of 35%

Severe Disease

879

Total County Need for SCU Beds in ACHs

Note 1 -- It is assumed that all mild and moderate disease persons requiring SCU in an ACH or NH are best served in the SCU in an ACH. It is assumed that 60 percent of those with severe disease are best served in a nursing home since many residents have significant other disease comorbidities requiring nursing home care.



**Estimates of Alzheimer's SCU Bed Need--FOR VALIDATION PURPOSES**

(Based on 2017 Draft MFP 2020 Population Estimates and July 1, 2016 UNC Study Estimates)

**Wake County**

	Age 65 to 74 (2020)		Age 75 to 84 (2020)		Age 85 + (2020)	
	Percent	Total	Percent	Total	Percent	Total
<b>2020 Population Estimate (2017 Draft MFP)</b>		85353		37994		14153
<b>Persons With ADRD By 2020</b>						
	3%	2561	17%	6459	34%	4812
<b>Mild Disease</b>	40%	1024	30%	1938	25%	1203
<b>Moderate Disease</b>	30%	768	30%	1938	30%	1444
<b>Severe Disease</b>	30%	768	40%	2584	45%	2165
<b>Persons Requiring LTC Services</b>		2048		5490		4211
<b>Mild Disease</b>	50%	512	50%	969	50%	602
<b>Moderate Disease</b>	100%	768	100%	1938	100%	1444
<b>Severe Disease</b>	100%	768	100%	2584	100%	2165
<b>Persons Requiring ACH or NH</b>		410		1427		1684
<b>Mild Disease</b>	20%	102	26%	252	40%	241
<b>Moderate Disease</b>	20%	154	26%	504	40%	577
<b>Severe Disease</b>	20%	154	26%	672	40%	866
<b>Persons Requiring SCU in ACH (Note 1)</b>		111		359		408
<b>Mild Disease</b>	35%	36	35%	88	35%	84
<b>Moderate Disease</b>	35%	54	35%	176	35%	202
<b>Severe Disease</b>	40% of 35%	22	40% of 35%	94	40% of 35%	121
<b>Total County Need for SCU Beds in ACHs</b>				877		

**Note 1 --** It is assumed that all mild and moderate disease persons requiring SCU in an ACH or NH are best served in the SCU in an ACH. It is assumed that 60 percent of those with severe disease are best served in a nursing home since many residents have significant other disease comorbidities requiring nursing home care.