



Cleveland's Long-term Care Continuum: Capacity and Need



Prepared for Age-Friendly Cleveland by a team from The Center for Community Solutions that included Loren Anthes, Emily Campbell, Emily Muttillo and William Tarter, Jr.

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Introduction

The City of Cleveland was the first municipality in Ohio to join the World Health Organization's Global Network of Age Friendly Cities and the AARP Network of Age Friendly Communities. Cleveland is home to more than 70,000 residents age 60 and older, who have a wide range of characteristics, abilities, strengths and needs. This number is likely to grow over time as people are living longer and healthier lives. Age-Friendly Cleveland is led by the City of Cleveland Department of Aging with substantial support from groups across the community. An Age-Friendly Cleveland Advisory Council was formed to guide the assessment and planning phases. Cleveland undertook a comprehensive assessment of community need in 2015 and spent the following year developing a plan, using the five-part cycle developed by WHO as a guide to engage in the process of becoming more age-friendly.

The Age-Friendly Cleveland Action Plan is built on the key findings from the Age-Friendly Cleveland Assessment. The plan is comprised of 21 strategies spread across three years of implementation. Examining the long-term care continuum was one of these strategies. During the planning phase, stakeholders recognized that long-term care is a key part of the aging services network. However, unlike many other areas, there was not a clear agenda or set of activities which would improve long-term care for people of all ages in Cleveland.

The Center for Community Solutions was identified as the lead agency for this strategy, which seeks to understand the long-term care continuum within the City of Cleveland. Community Solutions spent much of 2018 collecting and compiling information about long-term care within the City of Cleveland, including key informant interviews, examining national and state data on long-term care and developing methodologies to estimate need and ability to pay. This report is meant to increase understanding of needs and gaps relating to long-term care in the community. Ultimately, the desired future state is that residents have options along the continuum within Cleveland so they are not forced to move out of the community as their needs increase.

Many older adults will require long-term care as they age. Nursing homes and other institutional settings were once the standard model for this type of care. Over the past several decades, long-term care has shifted out of institutions and into the community. Reductions in the number of nursing facility beds that are supported by public programs, and an increase in the availability of home and community-based services, enables more people to remain in their homes and age in place, even if they cannot live completely independently. This shift toward home and community-based services has been positive for many older adults, especially as more than 90 percent of Cleveland older adults said it is important to them to be able to remain in their neighborhood as they age.

The Age-Friendly Cleveland assessment found that, overall, 56 percent of older adults in Cleveland reported that in the event that they need to move out of their home due to health or mobility issues, they were unsure that they could find a care facility or nursing home to meet their needs. In addition, many Age-Friendly Cleveland advisory committee members expressed concern about the supply of long-term care locations across the spectrum, and wondered if what was currently available was adequate to meet a need that is likely to grow. Cleveland could lose residents because high-quality, affordable long-term care options are not available within the city limits. The result: when it comes time for people to seek higher levels of care and move out of the home they had once lived in independently, they are forced to move out of the city all together, separating them from personal community-based networks.

Defining the long-term care continuum

As Community Solutions embarked on this research, it became increasingly clear that there is no standard definition for what comprises long-term care. Developing an understanding of the long-term care continuum requires an understanding of what is meant by the phrases "long-term care" and "continuum of care." The chart below lists the definition of terms by various government and managed care organizations that are related to long-term care delivery for residents of Cleveland.

- **Medicare**¹: Long-term supports and services can be provided at home, in the community, in assisted living or in nursing homes. Services, that include medical and non-medical care, are provided to people who are unable to perform basic activities of daily living, like dressing or bathing. Individuals may need long-term supports and services at any age. Medicare and most health insurance plans don't pay for long-term care.
- Administration on Aging²: Long-term care is a range of services and supports you may need to meet your personal care needs. Most long-term care is not medical care, but rather assistance with the basic personal tasks of everyday life, sometimes called activities of daily living. Other common longterm care services and supports are assistance with everyday tasks, sometimes called instrumental activities of daily living.
- Ohio Department of Medicaid³: Long-term services and supports are programs or services that help older adults and people with disabilities accomplish everyday tasks. These tasks may include bathing, getting dressed, fixing meals and managing a home. As our population ages, the number of individuals who need this kind of help will increase. Long-term services and supports allow individuals to live healthy, secure and independent lives either in a long-term care facility or in a home and community-based setting.
- Ohio Department of Aging⁴: Long-term care helps meet health or personal needs and can be provided at home in the community, in supportive living facilities like adult care homes, in assisted living or in nursing homes.
- Ohio Administration Code⁵: "Long-term care services" means the services provided by long-term care facilities or provided by community-based long-term care providers.

¹ <u>https://www.medicare.gov/coverage/long-term-care</u>

² <u>https://longtermcare.acl.gov/</u>

³ https://medicaid.ohio.gov/FOR-OHIOANS/Programs#623546-long-term-care

⁴ <u>https://ltc.ohio.gov/</u>

⁵ <u>http://codes.ohio.gov/oac/173-14-01</u>

- **CareSource MyCare Ohio Member Handbook**⁶: Long-term support services: Sometimes referred to as waiver services, these include things such as home delivered meals, emergency response services and adult daycare. These are services to help eligible members live independently.
- Buckeye MyCare Ohio Member Handbook⁷: Long-term services and supports: Long-term services and supports include long-term care and Home and Community Based Service (HCBS) waivers. HCBS waivers can offer services that will help you stay in your home and community.
- United HealthCare MyCare Ohio Member Handbook⁸: Long-term services and supports are services that help improve a long-term medical condition. Most of these services help older adults stay in their homes so they don't have to go to a nursing home or hospital.
- Ohio Department of Insurance Guide to Long-Term Care Insurance⁹: Long-term care (LTC) is the help older adults may need if they are no longer able to care for themselves. They may need long-term care if they have a prolonged physical illness, a disability or a cognitive impairment such as Alzheimer's disease. One may think long-term care is given only in nursing homes, but the term now applies to services that can be provided in a variety of settings. LTC services may include help with activities of daily living, home health care, respite care, hospice care, adult daycare, nursing home care and assisted-living facility care. LTC is different from traditional medical care. It helps one live as he or she is now and may not help to improve or correct medical problems.
- **Center for Medicare & Medicaid Services**¹⁰: A variety of services that help people with health or personal needs and activities of daily living over a period of time. Long-term care can be provided at home, in the community, or in various types of facilities, including nursing homes and assisted-living facilities. Most long-term care is custodial care. Medicare doesn't pay for this type of care if this is the only kind of care you need.
- Administration for Community Living¹¹: Services that include medical and non-medical care for people with a chronic illness or disability. Long-term care helps meet health or personal needs. Most long-term care services assist people with activities of daily living, such as dressing, bathing and using the bathroom. Long-term care can be provided at home, in the community, or in a facility. For purposes of Medicaid eligibility and payment, long-term care services are those provided to an individual who requires a level of care equivalent to that received in a nursing facility.
- HealthCare.gov¹²: Services that include medical and non-medical care provided to people who are unable to perform basic activities of daily living such as dressing or bathing. Long-term services and supports can be provided at home, in the community, in assisted living or in nursing homes. Individuals may need long-term supports and services at any age. Medicare and most health insurance plans don't pay for long-term care.

⁶ <u>https://www.caresource.com/documents/2018-medicare-medicaid-member-handbook-with-anoc-508/</u>

⁷ https://mmp.buckeyehealthplan.com/content/dam/centene/Buckeye/mmp/pdfs/H0022_18_MHR_Approved.pdf

⁸ <u>https://www.uhccommunityplan.com/content/dam/communityplan/plandocuments/2018/eoc/en/2018-OH-EOC-</u> <u>MMP-EN.pdf</u>

⁹ https://www.insurance.ohio.gov/Consumer/OCS/CompleteGuides/Complete Guide LTCare.pdf

¹⁰ <u>https://www.cms.gov/</u>

¹¹ <u>https://acl.gov/</u>

¹² <u>https://www.healthcare.gov/glossary/long-term-care/</u>

- **Care Conversations**¹³: Long-term care a broad spectrum of medical and support services provided to people who have lost some or all capacity to function on their own, and who are expected to need such services over a prolonged period of time.
- Office of the Assistant Secretary for Planning and Evaluation (U.S. HHS)¹⁴: Range of medical and/or social services designed to help people who have disabilities or chronic care needs. Services may be short- or long-term and may be provided in a person's home, in the community, or in residential facilities (e.g., nursing homes or assisted living facilities).
- **City of Cleveland Department of Aging**¹⁵: Long-Term Care Options Counseling provides information related to housing choices, types of assistance needed, care and help providers and paying for help. One-on-one consultations are provided to weigh through options for each unique situation, considering personal values, resources and preferences.

While many of the organizations above have a definition of long-term care, few define the continuum of care. The Healthcare Information and Management Systems Society describes the continuum of care as "a concept involving a system that guides and tracks patients over time through a comprehensive array of health services spanning all levels and intensity of care. The continuum of care covers the delivery of health care over a period of time and may refer to care provided from birth to end of life. Health care services are provided for all levels and stages of care." Under this model, care includes extended care, acute hospital care, ambulatory care, home care, outreach, wellness and housing. The integration of care happens through four basic mechanisms; planning and management, care coordination, case based financing and integrated information systems.¹⁶

In addition to formal and codified definitions of long-term care, the Age-Friendly Cleveland Advisory Council (the Council) provided feedback on what it perceives to be included in the long-term care continuum within the City of Cleveland. The Council consists of leadership from agencies that specifically serve older adults as well as those who serve this population alongside the general population. The Council includes representation of the various Age Friendly domains as identified by the World Health Organization and AARP. The perspective offered by the Council therefore represents a diverse range of experiences and professional backgrounds.

Through a guided conversation, the Council identified a number of conceptual and practical aspects of what a well-functioning long-term care continuum in Cleveland should include. Council members emphasized that long-term care can be provided in a variety of settings, at any age, to those with or without disability who need differing levels of care. There was agreement that long-term services and supports should be client-centered, prioritize the dignity of the individual and, when possible, provide them with choices about how to maintain independence. Long-term care involves care coordination and options for counseling to ensure the individual receives the appropriate level of care through transitions. Strong support systems, case management and prevention through education and resources can reduce or delay the need for more intensive services and supports. Finally, the types of Long-term services and supports available to an individual depends upon the payment source.

¹³ <u>https://careconversations.org/</u>

¹⁴ https://aspe.hhs.gov/

¹⁵ www.city.cleveland.oh.us/aging

¹⁶ <u>https://www.himss.org/definition-continuum-care Accessed 11/26/2018</u>

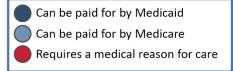
By combining the key features from the multiple definitions of long-term care with the concept of a continuum of care, a working definition of the long-term care continuum for the purposes of this report includes the following:

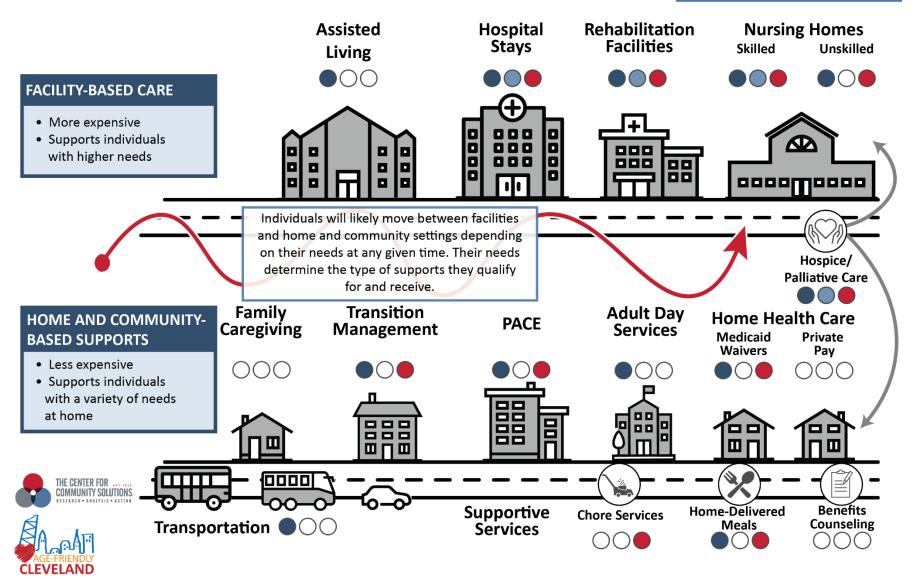
- Medical and non-medical services
- A variety of settings
- Assistance with activities of daily living
- Reflects personal values and preferences
- Serves persons any age
- Addresses both disability and chronic needs
- Includes services that are not covered by Medicare
- Incorporates care coordination
- Provides a range of services
- Individuals have choices in care and options counseling
- People have freedom to progress without a goal to improve or correct medical problems

The wide range of conceptual and practical aspects of long-term care services and supports are met with an equally diverse system of delivering supports along the continuum. As will be discussed in other sections of this report, each piece of the continuum is necessary for developing a well-functioning system. Not all of those who enter the continuum will visit each point for service, nor will they necessarily be visited in a linear fashion by any given individual. Instead of thinking of the continuum as a linear path, it is more realistic to consider it as universe of both known and unknown planets of support orbiting the individual with multiple points of entry and exit. A common base knowledge of the of services and facilities available in Cleveland, as well as the policies that govern them, will allow for an informed analysis of community need, current utilization and ability of the system to meet the need.

LONG TERM CARE CONTINUUM IN CLEVELAND

The long term care continuum is comprised of all of the programs, services and supports that are available to older adults as they age. The Age-Friendly Cleveland advisory council recommends that these supports should be client-centered, prioritizing the dignity of the individual and when possible providing them with choices on how to maintain independence.





Current utilization of long-term services and supports

Although the point where people enter long-term care and the time spent in the system is not linear, the following section is organized from lowest to highest needed level of care. Wherever possible, data is provided at the county or city level. There is much more information available on providers and services that are regulated by government or covered by Medicare fee-for-service. Unfortunately, this misses large components of the long-term care continuum, most notably family caregiving. With the exception of nursing facilities, there is also little information on quality. Even so, this report represents the first time that information about many aspects of the long-term care continuum have been gathered together in one place together with data on utilization.

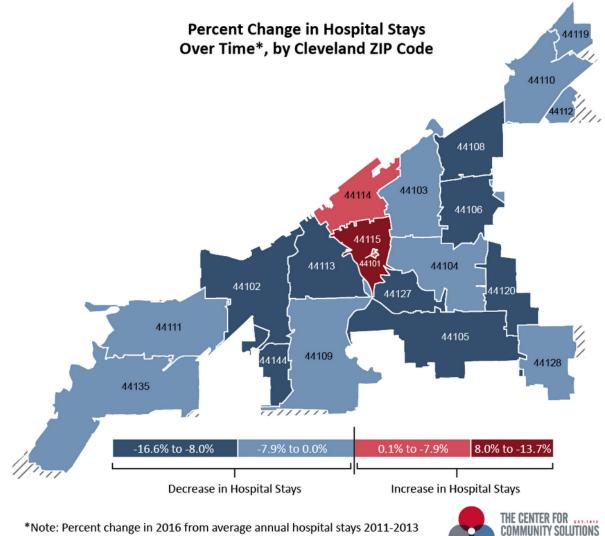
Depending on the type of service and the setting of the service delivery, long-term care may be provided by a provider or facility that has been licensed to provide that service. However, it is important to note that not all long-term care services are subject to a licensing administration. Family caregiving, assisted living, homemaker services and rehabilitation facilities are among some of the services that do not require licensure to provide. The table below provides the number of each type of licensed facility located within the City of Cleveland, followed by a section providing details about the various mediums of long-term care service delivery.

Facility Type (Licensed only)	Number in the City of Cleveland
Adult Day Service Centers	3
HCBS Individual Providers	13
Home Health Agencies	19
Hospice Service Providers	9
Hospitals	7
Nursing Facilities	26
PACE	1
Residential and Assisted Living	13
ODA Waiver Providers	13
ODM Waiver Providers	9
Physical Therapy and Speech	3

Hospital stays

The need for long-term care for many older adults begins with a health event that results in a hospital stay for acute care. In recent years, it appears acute care stays for residents of Cuyahoga County are declining with a reduction of nearly 10,000 stays, or nearly 13 percent, from 2012 through 2016. There were 74,142 such stays in 2012, a number that dropped to 64,650 in 2016.¹⁷ As shown on the map below, hospital stays for older adults fell in most ZIP codes within Cleveland, but there are a few exceptions, with the largest increases are observed in the Central and Downtown areas. These trends could be the result of more services provided in outpatient settings, which do not require overnight hospital stays.

¹⁷ Cuyahoga County Community Health Assessment/CHNA 2018. file:///G:/2018%20Joint%20Cuyahoga%20CHNA Final.pdf



Source: 2018 Cuyahoga County Community Health Assessment

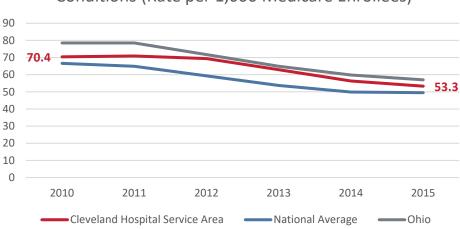


There are several hospitals within city limits, including three in the Cleveland Clinic system (Main Campus, Fairview and Lutheran), MetroHealth Medical Center, Saint Vincent Charity Medical Center and University Hospitals Cleveland Medical Center. There are adequate facilities for hospital stays within the City of Cleveland, but the closure of some smaller facilities, and changes to public transportation, mean that it is more difficult for older adults in some neighborhoods to access these services.

Preventable hospital stays for ambulatory, care-sensitive conditions,¹⁸ which are preventable with good access to primary care, have fallen in recent years for Medicare enrollees, most of whom are older than age 65. Rates in the Cleveland Hospital Service Area remain between state and national averages.¹⁹

¹⁸ These include Convulsions, Chronic Obstructive Pulmonary Disease, Bacterial Pneumonia, Asthma, Congestive Heart Failure, Hypertension, Angina, Cellulitis, Diabetes, Gastroenteritis, Kidney/Urinary Infection and Dehydration.

¹⁹ Dartmouth Atlas, The Dartmouth Institute for Health Policy and Clinical Practice. https://atlasdata.dartmouth.edu/



Discharges for Ambulatory Care-Sensitive Conditions (Rate per 1,000 Medicare Enrollees)

Data Source: Dartmouth Atlas

Nationally, individuals age 65 and older represent the largest segment of people with at least one overnight hospital stay in 2016. For all age groups, those who are uninsured have the lowest rates of hospitalization. The Midwest has the highest rates of hospitalization of any region, regardless of insurance status.²⁰ One-third of all hospital discharges nationally are for individuals age 65 and older, and nearly 13 million older adults are hospitalized each year. Adverse drug events, which are medically-related drug interventions that result in injuries, like an allergic reaction or overdose, occur in 15 percent or more of older patients, half of which are preventable. This number increases to 1 in 3 for adults older than age 70.²¹

Family caregiving

Providing care for a loved one is a role that often comes with little to no training or preparation to address the complex needs of the person and the intricacies of the system of long-term services and supports. Caregivers interviewed for this report described the challenges of navigating a multifaceted system of agencies, both public and private, to coordinate the care necessary to meet the needs of their care recipient in a way that is affordable and safe. Family caregivers often handle the transitions between various medical and home settings. While some caregivers are equipped with the knowledge, patience, time, resources and emotional stability to effectively manage transitions and care coordination, many are not. Caregivers report high levels of exhaustion and feelings of guilt. This type of caregiver stress is also directly tied to average length of stay for inpatient hospital admissions among those to whom they are providing care. To lower the length of stay, services that expedite discharge planning and encourage respite for caregivers of older adults who have been hospitalized can lower stress and thus improve outcomes and lower costs.²²

https://ftp.cdc.gov/pub/Health Statistics/NCHS/NHIS/SHS/2016 SHS Table P-10.pdf.

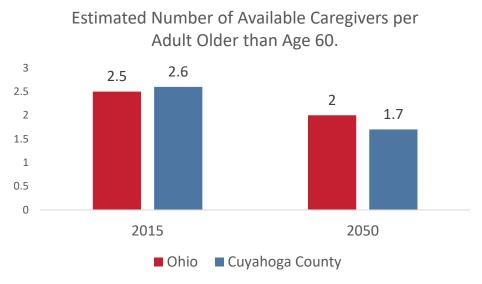
²⁰ United States. U.S. Department of Health and Human Services. The Center for Disease Control. Summary Health Statistics: National Health Interview Survey, 2016.

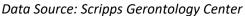
²¹ Pretorius, Richard W., Gordana Gataric, Steven K. Swedlund, and John R. Miller. "Reducing the Risk of Adverse Drug Events in Older Adults." AAFP Home. March 01, 2013. <u>https://www.aafp.org/afp/2013/0301/p331.html</u>

²² Toh, Hui Jin, Zhen Yu Lim, Phillip Yap, and Terrance Tang. "Factors Associated with Prolonged Length of Stay in Older Patients." Singapore Medical Journal 58, no. 3 (2017): 134-38.

Family caregiving is a vitally important component of the long-term care continuum. In Ohio, the value of the services provided by unpaid caregivers represents 78 percent of the total value of long-term care services delivered.²³ About 10 percent of Americans have provided unpaid care to an adult over the age of 50 in the last 12 months, the value of which exceeds that of paid home care and total Medicaid spending.²⁴ Caregivers spend the majority of their time on routine activities such as shopping, food preparation and household chores. For caregivers that provide care for individuals with complex, chronic needs, nearly half perform medical tasks and nearly all provide assistance with activities of daily living.²⁵

Since the vast majority of family caregiving is unpaid and unregulated, there is no data on how many individuals in Cleveland provide or benefit from family caregivers. However, the Scripps Gerontology Center at Miami University has estimated the number of potential caregivers available per older adult and found that Ohio is below average.²⁶ The decline in the number of available caregivers is driven by the increase in the number of older adults. While Cuyahoga County currently has more availability than the state as a whole with 2.6 caregivers per older adult, that availability will decline to a level of 1.7 by 2050, below the state average. Caregiving is often a 24-hour collaborative job with many family members contributing to various aspects of the care. With the number of available caregivers declining, alternative methods to meet the need for in-home care and/or additional supports for those providing care will need to be developed.





Since poverty rates in Cleveland are high, it is likely that family caregivers may be less equipped to take on the financial burden of caring for a loved one. In a national study, 76 percent of non-professional caregivers reported making adjustments to their work schedules, including taking on fewer hours, quitting their jobs or retiring. Thirty-two percent of caregivers with household incomes below \$25,000

²³ Ohio Department of Aging, Caregiver Support, <u>https://aging.ohio.gov/caregiversupport</u>

²⁴ Mehdizadeh, Shahla. *Unpaid Caregivers: Growing Demand and Limited Supply*. Issue brief. Scripps Gerontology Center, Miami University. September 26, 2016.

²⁵ "Caregiver Statistics: Demographics." Caring for Adults with Cognitive and Memory Impairment, *Family Caregiver Alliance*. <u>https://www.caregiver.org/caregiver-statistics-demographics</u>

²⁶ Mehdizadeh, Shahla. *Unpaid Caregivers: Growing Demand and Limited Supply*. Issue brief. Scripps Gerontology Center, Miami University. September 26, 2016.

indicated that their financial situation had worsened since becoming a caregiver and only 56 percent of caregivers at all income levels rate their financial well-being as excellent or good. ²⁷

Home care

Long-term care services provided in the home can be medical or non-medical and can be directed toward the individual or towards an individual's living environment. In Cleveland, home-based services may be provided by the staff of a for-profit agency, a nonprofit agency, a managed care organization, an independent caregiver, volunteer or a government office. Home care includes home health care, homemaker services and aging supportive services. The payment method depends on the type of service and may be covered by Medicare, Medicaid, subsidized through government funding, provided through charity or paid through private funds.

The Medicare home care benefit is considered health care and must be deemed medically necessary. Medicare will cover a limited amount of home health care when it is part of a plan created by an individual's doctor and includes either skilled nursing care, physical therapy, speech-language pathology or continued occupational therapy. The individual's doctor must also certify that the individual is homebound. Medicare's home health care benefit does not include 24-hour a day care, home-delivered meals, custodial or personal care or homemaker services. Medicare lists 141 home health care agencies that serve Cleveland; 88 are based in Cuyahoga County. Sixteen of the agencies that are registered with Medicare to provide services in Cleveland have business addresses listed in the City of Cleveland. Of the 16 Cleveland-based agencies, data was available for five agencies through Medicare's data website.²⁸ While this data is not robust enough to give us a clear picture of how many of Cleveland's older adults access home health care through Medicare, it does help provide context to frequency and type of home health services that are reimbursed by Medicare. In 2016, 2,359 unduplicated beneficiaries received home health care with an average number of 21.2 total visits per 60 day episode, with skilled nursing utilized the most, followed by physical therapy, home health aides, occupational therapy and speech therapy.

Home-based long-term care services paid by Medicaid are delivered through waiver programs, primarily through Pre-Admission Screening Providing Options and Resources Today (PASSPORT). A listing of community and home-based services can be found in the Medicaid waiver section, below.

Older adults in Cleveland can receive a variety of aging supportive services that are either covered completely, or subsidized, by government funds. The Older Americans Act, Community Service and Community Development Block Grants and the Cuyahoga County Health and Human Service tax levy all provide funding for non-medical support services designed to help older adults maintain independence in their homes. These services are delivered by county, city and nonprofit employees and include homemaker services, home delivered meals, seasonal outdoor maintenance, home modifications, information and referrals, benefits counseling, long-term options counseling and transportation. The Cuyahoga County Department of Senior and Adult Services also subsidizes home care services through the Options for Independent Living program.

An unknown number of agencies that include Cleveland within their service area provide non-medical homemaker services. These agencies are not required to be licensed by the state nor certified through

 ²⁷ The Many Faces of Caregivers: A Close-up Look at Caregiving and Its Impacts, Transamerica Institute, 2017
 ²⁸ Medicare Home Health Agency (HHA) Provider Aggregate Report, CY 2016

the Center for Medicare and Medicaid Services. Without an administrating agency, there is no mechanism for registering or reporting utilization rates. The homemaker services typically offered through these agencies are privately paid and include cooking, laundry, shopping, running errands, cleaning and companionship care.

Cleveland has developed a robust network of social services, provided through charity and philanthropy, which often act as long-term supports for some older adults. These supports include hot meal programs and food pantries, volunteer companionship, clothing distributions, home repair programs, utility and rental assistance, among other services. United Way's 211 and the Aging and Disability Resource Centers play a vital role in connecting older adults to these services.

Rehabilitation facilities

Rehabilitation facilities provide some combination of diagnostic, therapeutic and restorative services in order to help people who are disabled, injured or sick recover. There are three types of rehabilitation facilities: Comprehensive Outpatient Rehabilitation Facilities (CORF), Outpatient Physical Therapy or Speech Pathology Services (OPT/SP) and Inpatient Rehabilitation Facilities (IRF). Of the three, IRFs are the only ones that require a license under Ohio law. An IRF provides specialized rehabilitation services on an inpatient basis to people with functional limitations or chronic disabling conditions. All patients in IRFs must be capable of tolerating a minimum of three hours of rehabilitation therapy five days a week. Depending on their medical condition, older adults who leave the hospital may need to stay in an IRF in order to regain the level of functionality required to be in a home or community-based setting.

There are currently three IRFs licensed and operating within the City of Cleveland, MetroHealth Medical Center, the Cleveland Clinic and Hanna House Inpatient Rehab Center. Medicare's website provides data on the number of times people covered by Medicare with specific medical conditions were treated in the last year at each facility. Of the three facilities, only two provided data to Medicare for the most recent reporting period. Hanna House Inpatient Rehab Center did not provide data.

Medical Conditions	MetroHealth Medical Center	Cleveland Clinic Main Campus
Stroke	94	35
Nervous system disorder (excluding stroke)	Less than 11*	30
Brain disease or condition (non-traumatic)	13	32
Brain injury (traumatic)	36	less than 11 *
Spinal cord disease or condition (non-traumatic)	29	less than 11 *
Spinal cord injury (traumatic)	21	Not Available
Hip or femur fracture	15	Less than 11 *
Hip or knee replacement, amputation or other bone or joint condition	91	13
All other conditions	Less than 11 *	80

*Data is suppressed for counts 10 or less.

Medicaid Waivers for Home and Community Based Services

Home and community based waiver services (HCBS) provide opportunities for Medicaid beneficiaries to receive services in their homes or communities rather than in institutions or other isolated settings. Waiver programs waive the requirements that certain levels of care be provided in a nursing facility, and those available to Cleveland residents are administered by the Western Reserve Area Agency on Aging (WRAAA). The HCBS waivers prescribe the types of services, dependent on the individual's assessment of need conducted by WRAAA.

These waivers are designed to reallocate dollars for institutional settings towards community-based options for older adults and for individuals with disabilities. Currently, the state has three "aging" waivers, though it should be noted there are a number of older adults who have a developmental disability and access a different type of waiver, depending on their need. The chart below provides a description of the three aging waivers operating in the state of Ohio:

Medicaid Waiver Capacity in Ohio

Waiver Name	Ohio Home Care Waiver	PASSPORT	Assisted Living
Capacity	8,600	32,031	5,078
Enrollment	5,817	21,314	3,283
Average Cost	\$18,290	\$9,363	\$11,651
Eligibility Requirements Services	Specific Financial Criteria, Nursing Facility Level of Care, Age 59 or Younger • Adult day health	Specific Financial Criteria, Nursing Facility Level of Care, Age 60+ • Adult day health	Specific Financial Criteria, Nursing Facility Level of Care, Age 21 or Older • Assisted-living services
	 Addit day hearth Emergency response Home care attendant Home delivered meals Home modification Out-of-home respite Personal care aide Supplemental adaptive and assistive devices Supplemental transportation Waiver nursing 	 Addit day hearth Alternative meal service Choices home care attendant Chores Community transition Emergency Response system Enhanced community living Home care attendant Home delivered meals Home medical equipment and supplies Independent living assistance Minor Home Modification, Maintenance and Repair Non-medical transportation Nutritional consultation Out of Home Respite Personal Care Pest control 	 Community transition (for nursing home residents only)

		 Social work and counseling 	
		TransportationWaiver Nursing	
Administration	Ohio Department of Medicaid	Ohio Department of Aging	Ohio Department of Aging

Cleveland has about 6,550 individuals who consume HCBS services, and none of the waivers are currently at capacity.²⁹ However, information gathered from key informants working in the field of aging, and from older adults, indicates that difficulties navigating the system and a lack of consumer choice may present challenges for older adults who could benefit from waiver services.

Adult day services

Adult day services are typically one of three types: social, dementia-related and medical. The latter requires a doctor's assessment and has medical personnel on site. Many adult day services are reimbursable through a Medicaid HCBS waiver, though they are also reimbursable through the Veteran's Administration, or many private insurance plans. Other individuals pay privately. These services are not available through Medicare.

In Ohio, adult day services reimbursed through private insurance or private pay are not required to be licensed or certified. However, adult services administered at adult day centers that receive payments through Medicaid waivers are certified by the Ohio Department of Aging. Requirements are found in the Ohio Revised Code which states the following: "Adult day service' ('ADS') means a regularly-scheduled service delivered at an ADS center, which is a non-institutional, community-based setting. ADS includes recreational and educational programming to support an individual's health and independence goals; at least one meal, but no more than two meals per day; and, sometimes, health status monitoring, skilled therapy services, and transportation to and from the ADS center."³⁰

More than 53 percent of individuals in adult day services have a diagnosis of Alzheimer's disease or another cognitive impairment. Adult day service beneficiaries have higher rates of chronic diseases such as hypertension, physical disability, cardiovascular disease, diabetes and developmental disabilities. There are currently no waiting lists in Medicaid for access to adult day services³¹

Older adults in Cleveland who opt to remain in their homes and require a high level of supervision may find adult day services particularly useful, especially if a family caregiver works outside the home or needs a respite from caregiving. There are three adult day facilities in Cleveland that accept Medicaid waivers; Acacia Place Adult Day Center, Eldercare Services Institute and Eliza Bryant Village. Acacia Place and Eldercare Services can both accommodate up to 30 individuals at a time. At the time of this report, both had openings for between 5 to 15 people daily. Because centers that operate outside of the Medicaid reimbursement system are not licensed or certified, there is no comprehensive list available. Based on information shared by key informants and internet searches, it appears there are a number of small, privately-run adult day programs operating within the city.

²⁹ Ohio Medicaid Waiver Comparison Chart – Enrollment Figures for August 2018

Mehdizadeh, S., Nelson, M., Applebaum, R., Straker, J.K. (2017) Policy Does Matter: Continued progress in providing long-term services and supports for Ohio's older population. Scripps Gerontology Center, Miami University. August 2017. ³⁰Ohio Administrative Code accessed on 11/20/208 <u>http://codes.ohio.gov/oac/173-39-02.1</u>

³¹ 2016 National Study of Long-Term Care Providers; State Estimates for NCHS Data Brief 296

Program of All-inclusive Care for the Elderly (PACE)

The Program of All-inclusive Care for the Elderly (PACE) is a unique type of managed care program built on an HCBS model. There is currently only one PACE program in Ohio, McGregor PACE. This program provides all of the medical and ancillary services for participants at a capitated, or a fixed and prearranged, rate, which is a cumulative dollar amount based on the number of people enrolled. The program is open to residents of Cuyahoga County that meet eligibility criteria. About 400 individuals are served through this program. This is in addition to the 6,550 individuals who receive services through Ohio's three other HCBS waiver programs.³²

The 400 enrollees in the PACE program have their care coordinated by an interdisciplinary team who works with participants and caregivers to develop a personalized plan of care. McGregor PACE uses a community-based approach to allow adults to remain in familiar surroundings while receiving the help they need. McGregor PACE currently has three service locations, two of which are located within the City of Cleveland. The PACE program allows an individual to remain with the same interdisciplinary team of care providers wherever they are on the long-term care continuum.

Assisted living

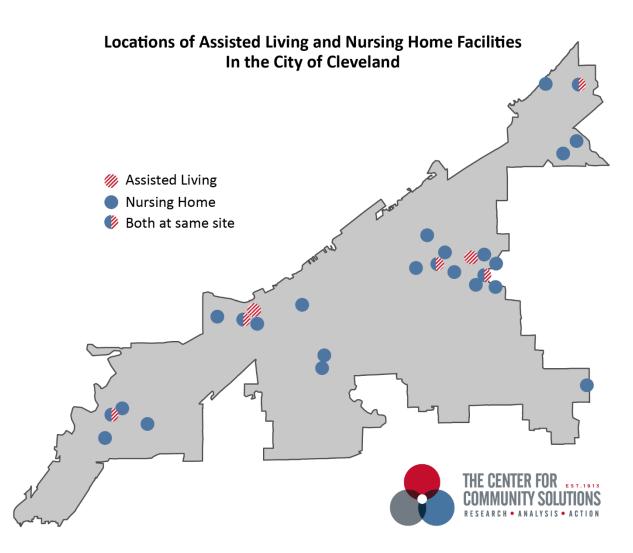
Assisted living facilities offer a housing alternative for older adults who may need help with dressing, bathing, eating and toileting, but do not require the intensive medical and nursing care provided in nursing homes. Assisted living facilities may be part of a retirement community, nursing home, senior housing complex or may stand-alone and if licensed by the state are considered residential care facilities. In Ohio, 720 residential care facilities are licensed and certified by the Ohio Department of Health³³ and accept the Assisted Living Waiver. Data provided by the Ohio Department of Aging's Long-Term Care Ombudsman shows eight residential facilities operate in Cleveland with a total of 480 beds. At the time of this report one of the residential care facilities, Vantage Place, Inc. was in the process of closing and relocating residents.

Assisted living facilities provide the supportive environment many older adults need when they do not have a medical need to live in a nursing facility. If an individual reaches the level of care that requires skilled nursing, the transition into that facility and potentially out of that facility, may be managed by a social worker or care coordinator through a waiver program.

Assisted Living Facilities in Cleveland	Beds
Vantage Place, Inc.	86
Judson Retirement Community	132
Singleton Health Care Center	22
Slovene Home for the Aged	12
Judson Manor	30
Algart Assisted Living	47
St. Augustine Towers	110
West Park Commons	41
TOTAL	480

³² Mehdizadhe, S., Applebaum, R., Kunkel, S., Faust, P. (2012) <u>Evaluation of Ohio's Program of All Inclusive Care for the</u> <u>Elderly (PACE)</u>. Scripps Gerontology Center, Miami University

³³ <u>https://odh.ohio.gov/wps/portal/gov/odh/know-our-programs/residential-care-facilities-assisted-living/residentialcarefacilitiesassistedliving</u>



As the map shows, assisted living and nursing home facilities tend to be clustered within specific neighborhoods in the City of Cleveland. Therefore, needy older adults in other parts of the city will be forced to leave the neighborhoods they have called home in order to find appropriate levels of care.

Nursing facilities

Nursing facilities are a guaranteed and highly utilized Medicaid benefit. While Medicare covers short stays in nursing facilities, only Medicaid covers long-term stays. In Ohio, there are 963 licensed facilities with 84,000 beds. It should be noted, however that the number of individuals under age 65 who use nursing facilities is growing, and Ohio's number of these individuals is higher than the national average. In the Medicaid program, which is the predominant payer of nursing home services, the primary diagnosis that seems to be driving this trend is severe mental illness, suggesting nursing homes are serving as a de facto provider for many aging individuals who have a behavioral health issue that is not resolved in a community setting. While Ohio is the seventh largest state in terms of overall population, it is the third largest state, behind Texas and California, in the number of licensed nursing homes.³⁴

 ³⁴ Nelson, Ian, and John Bowblis. <u>A New Group of Medicaid Nursing Home Residents: The Unexpected Trend of Those</u> <u>Under Age 65 Using Nursing Homes in Ohio</u>. Issue brief. Scripps Gerontology Center, Miami University. November 9,
 2017. Accessed October 12, 2018. Canigla, J., Corrigan, J.E. (2017, March) <u>Ohio nursing homes among the nation's lowest</u> rated in quality of care: A critical choice.

Nursing home facilities have additional layers of complexity including certificates of need, quality ratings and staffing and inspection requirements that can impact their ability to meet the needs of the community.

Certificate of Need

The State of Ohio's Certificate of Need Program (CON) laws are intended to control costs in health care expenditures by regulating the number and availability of long-term care facilities. As populations change within the state, bed supply need varies widely by county. These changes led to 2008 legislation which changed the process of determining bed supply by revising processes designed to create a system to align the number of beds to the needs of the county. As a result, beds are periodically reallocated from one county to another.

During the initial realignment of beds in 2008, 4,100 beds were reallocated in Ohio and about 1,500 beds were decommissioned due to lack of use. Cuyahoga County did not have a surplus or deficit compared to the state average. In 2009, the state projected that the optimum number of beds licensed in Ohio was about 93,000. By 2015, despite the increase in the number of people age 65 or older, this number went down to 84,000 and the average occupancy rate declined. In addition to the CON, policies Ohio implemented to transition more individuals into community settings reduced the need for licensed beds.

Regulation continues to affect long-term care facilities and the beds within those facilities. Activities subject to regulation include the development, replacement or renovation (if more than \$2 million) of an LTC facility as well as the relocation of beds between facilities. Further regulation for the relocation of beds is outlined in Ohio Revised Code §3702.5 and plans are reviewable by the state. There is no limit on the number of beds that may be relocated within a county, but beds can only be moved across county lines every four years and are subject to scrutiny by the state. The next time this process will occur is in 2020.

In the most recent assessment, the optimum number of beds calculated by Ohio Department of Health decreased from 54 beds to 46 beds per 1,000 people older than age 65. Currently, Cuyahoga County has a surplus of 11 beds (57 per 1,000 people age 65 or older) and the statewide occupancy rate is 82.4 percent. By 2020, Ohio is projected to have 42 beds per 1,000 people, which is still above the national average. This projection includes the removal of 1,500 licensed beds. Since Ohio is increasingly moving towards providing Long-term services and supports in home and community-based settings, the reduction of licensed beds is not expected to significantly change occupancy rates in Ohio, nor in counties like Cuyahoga.³⁵

The chart below lists the dual certification nursing facilities currently operating in the City of Cleveland. The most recent data available, from the fourth quarter of 2017, shows an 84 percent occupancy rate. In 2015, there were a total of 2,494 stays for Medicare beneficiaries, averaging 25.3 days by 1,898 unduplicated beneficiaries.

³⁵ Mehdizadeh, S. Sauer, P.E., Nelson, M., Hua, C. (2018). <u>The impact of state nursing home bed relocation policy in Ohio.</u> Oxford, OH: Scripps Gerontology Center, Miami University

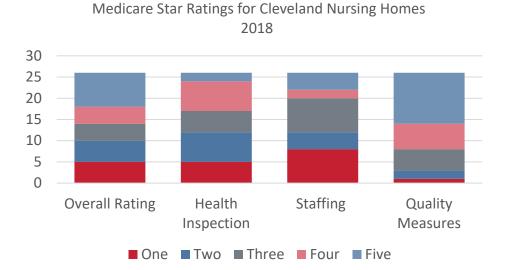
Skilled Nursing Facility	ZIP Code	Certified Beds	4th Q 2017 Residents	Total Stays 2015	Distinct Beneficiaries 2015	Length of Stay 2015
Algart Health Care	44102	72	69	*	*	*
Cityview Nursing & Rehab Center	44103	150	144	69	48	25.35
Crawford Manor Healthcare						
Center	44106	50	47	45	32	24.38
Eastbrook Healthcare Center	44112	132	68	18	14	22.06
Eliza Bryant Center	44103	175	155	116	84	28.15
Eliza Jennings Home	44102	126	112	125	84	25.81
Elisabeth Severance Prentiss Center	44109	150	143	270	208	19.33
Fairfax Health Care Center	44106	100	79	50	37	25.84
Franklin Plaza Extended Care	44113	201	153	54	38	21.43
Hanna House Skilled Nursing Center	44106	50	22	286	237	16.75
Hillside Plaza	44112	47	36	64	47	24.42
Judson Park	44106	83	54	167	124	25.19
Larchwood Village Retirement Community	44135	99	80	39	29	25.59
Manorcare Health Services- Euclid Beach	44110	149	146	63	44	32.97
McGregor At Overlook	44106	25	23	14**	11**	32.79**
Metrohealth System	44109	29	17	132	114	15.93
Rae-Ann West Park	44135	70	48	40	32	29.5
Rocky River Gardens Rehab & Nursing Center	44135	140	72	115	80	21.77
Select Specialty Hospital- Cleveland	44120	40	15	261	224	21.42
Singleton Health Care Center	44103	50	43	16	12	45.56
Slovene Home For The Aged	44119	142	135	141	107	32.82
St. Augustine Manor	44102	234	217	179	121	25.6
University Manor Health & Rehab	44106	149	167	65	51	24.23
Westpark Neurology & Rehabilitation Center	44135	143	123	49	39	27.47
Willow Park Convalescent Home	44122	135	116	71	49	25.46

*Data not provided by facility **Most recent data available was from 2014

Source: Public Insight, Insight for Healthcare, accessed 9/27/2018

Quality in nursing homes

The federal government maintains a database of licensed facilities in the United States that compares staffing and quality metrics in a number of areas.³⁶ Currently, more than 4 in 10 nursing homes in the State of Ohio are below average in at least one of the domains measured. The average overall rating of facilities in Cleveland was 3.23 out of a possible 5, with 40 percent of facilities having a star rating of one or two, and only four facilities achieve the highest overall score of five. Critics of this system cite issues with the longevity and sensitivity of tools used to make comparisons.



Overall Rating	Combines health inspection, staffing and quality measure ratings
Health Inspection	Weighted score from recent health inspections
Staffing	Staffing hours for RNs, LPNs, LVNs and nurse aides
Quality Measures	Data from a select set of clinical measures

Data Source: Medicare Nursing Home Compare

Staffing & inspections

Nursing home staffing levels, which are a key metric of the federal government's quality rating system, vary widely by state. Ohio's levels are consistent with national trends, with varied levels of staffing depending on which facility is examined. Other states, however, require more of facilities, including thresholds for hours spent per patient per day and levels of education and credentialing. Ohio also lags behind other states regionally and nationally in the number of inspectors available to audit facilities, meaning many facilities may not be inspected as often as they are elsewhere. Compared to statewide averages in these two areas, Cleveland-based facilities slightly underperform with staffing at 2.85 (compared to 2.87 statewide) and inspections at 2.62 (compared to 2.75 statewide).

Transition management

Nearly every point along the long-term care continuum involves a transition. Transitions generally involve a physical transition, when a person moves from one facility to another, as well as a change in

³⁶ Medicare Nursing Home Compare

the supports and services a person needs in a new setting. Transitional care is the care patients receive as they move between health care settings and providers; it bridges care gaps between different health care settings.³⁷ An important aspect of transition management is care coordination, which has been defined as *"the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient's care to facilitate the appropriate delivery of health care services."*³⁸ As medical needs become more complex, the number of medical professionals who meet those needs tends to increase. Care coordination ensures an individual continues to receive the recommended level of care while moving between physical locations by managing all aspects of medical care and supports necessary to maintain health.

In addition to care coordination, which is focused on medical care, older adults in transition often benefit from case management. Case management typically involves coordinating the social conditions that allow for a successful transition, particularly in home and community-based settings. Case managers are concerned with housing, food access, familial or community support, transportation and financial stability, all of which are social determinants that impact health.

Whether or not individuals can access care coordination and case management often depends on their payment sources and where they receive care. The PACE model includes care coordination and case management as do Medicaid waiver programs. It is difficult to estimate the unmet need for care coordination and case management in the community. Anecdotally, many providers in the aging network report an increasing number of older adults who would benefit from this type of service, but either do not qualify for it or do not know how to access it. It is likely that those who could benefit from, but lack access to, transition management have higher rates of re-hospitalizations and future health crisis. Below are two additional programs available to residents of Cleveland that provide some level of transitional management.

HOME Choice

Transition out of a nursing facility, hospital or a residential treatment facility can be eased by the Medicaid Helping Ohioans Move, Expanding Choice (HOME Choice) program. Individuals enrolled in Medicaid, but not in a waiver program, who have spent at least 90 consecutive days in a facility are eligible to receive assistance to return to a home or community-based setting through this program. HOME Choice operates through a team of professionals who assess readiness for living in a community-based setting, assist in finding appropriate housing and provide case management as the transition occurs. Ohio's HOME Choice program is part of the Money Follows the Person grant which expired in December 2018. Ohio continued funding the program for the first six months of 2019. In July of 2019 the program will be folded into existing Medicaid Waiver programs including MyCareOhio and PASSPORT.³⁹

Aging and Disability Resource Network

The Aging and Disability Resource Network (ADRN) provides services to anyone in the community, regardless of income. According to WRAAA, the ADRN is designed to "simplify the process and make

³⁷ Rennke, S., & Ranji, S. R. (2015). Transitional care strategies from hospital to home: a review for the neurohospitalist. *The Neurohospitalist*, *5*(1), 35-42.

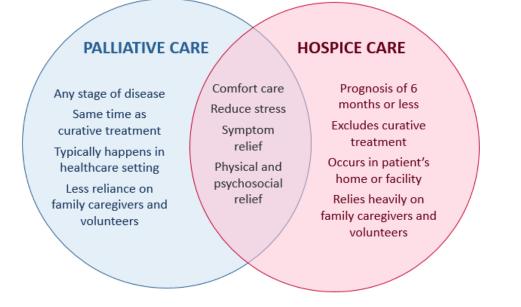
³⁸ McDonald KM, Sundaram V, Bravata DM, et al. Closing the Quality Gap: A Critical Analysis of Quality Improvement Strategies (Vol. 7: Care Coordination). Rockville (MD): Agency for Healthcare Research and Quality (US); 2007 Jun. (Technical Reviews, No. 9.7.) 3, Definitions of Care Coordination and Related Terms. Available from: <u>https://www.ncbi.nlm.nih.gov/books/NBK44012/</u>

³⁹ Council on Aging of Southwestern Ohio (October 2018) Changes coming to HOME Choice as federal funding end Retrieved from <u>https://www.help4seniors.org/News-Events/Blog/News/Archives/2018/10/Changes-coming-to-HOME-Choice-as-federal-funding-ends.aspx</u>

sure support connections between local agencies and individuals are made successfully." Aging and Disability Resource Centers (ADRC) within the ADRN provide distinct services to increase the opportunities for independence for older adults living in the community. The City of Cleveland's ADRC offers long-term care options counseling which "provides information related to housing choices, types of assistance needed, care and help providers and paying for help." Older adults and their families can access this program to learn about the long-term care services and supports available to them, possible sources of payment and eligibility for programs and payment sources. In 2017, Cleveland's Department of Aging assisted 362 people through long-term options counseling by working with individuals to create a long-term care plan based on their preferences, values and needs. This was an increase of 30 percent from the previous years, and nearly one-quarter of those who access this service are age 85 and older. The long-term options counselor coordinates with a number of agencies and services including home health care, hospital systems, EMS, pharmacies, home care supply delivery, mental health and legal services related to end-of-life documents.

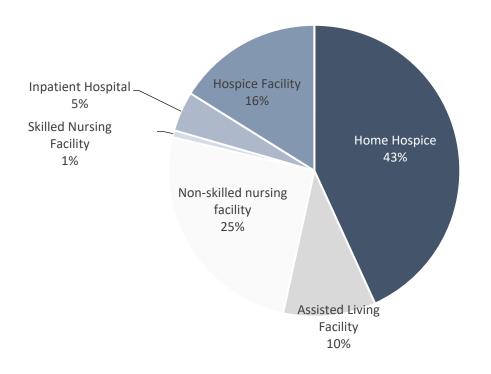
Palliative care and hospice care

Palliative care and hospice care are philosophies of care based on the concept of symptom relief to provide comfort to patients suffering from serious illnesses. Both types of care typically involve an interdisciplinary team which can include medical professionals, social workers, spiritual guidance and family members. Both consider the holistic nature of the patient and treat the physical, psychosocial, emotional and spiritual care of the person. While they have much in common, hospice care is provided without curative treatment while palliative care can be offered alongside curative treatment. Palliative care typically takes place in a medical setting whereas hospice care can occur wherever the patient lives, often within their own home. Both Medicare and Medicaid explicitly cover hospice care but neither use the term palliative care to describe benefit coverage. Often the recommended palliative services are covered under existing Medicaid and Medicare benefits. The similarities and differences are displayed in the chart below.



In Cleveland, the Hospice of the Western Reserve offers a standalone Hospice House with 40 suites, as well as services to meet patient needs, no matter where they live. Since hospice and palliative care are provided in a variety of settings alongside other medical care, there is no limit on the number of older adults who are able to access this care.

The Hospice Utilization and Payment Public Use File provides hospice data from 2016, which was submitted by hospice providers. The utilization data includes all beneficiaries served by location of provider, but not by patient residence. There are three agencies located within the City of Cleveland included in the data set; Judson Hospice, Visiting Nurses Association Hospice and Hospice of the Western Reserve. Of the 6,054 hospice beneficiaries these three agencies reported for 2016, 94 percent received hospice care through Hospice of the Western Reserve. The Hospice of the Western Reserve has a service area of 11 counties in Northern Ohio. While this data cannot provide specific utilization numbers for Cleveland residents, it does illustrate trends for the region. Sixty percent of the 2016 hospice beneficiaries from agencies based in Cleveland were women. Hospice provided in the home was the most common site of hospice service, followed by non-skilled nursing facilities and hospice facilities.



Site of Service for All Clients of Cleveland-based Hospice Providers, 2016

Data Source: Hospice Utilization and Payment Public Use File

Overview of recent policy developments

Local, state and national policy shapes the long-term care continuum, impacting settings for long-term care, service delivery models and methods of payment. Some aspects of the continuum are highly regulated, while others are not. A review of past and current policy is helpful to understand how the current system has developed, and can provide a glimpse into the future of long-term care in Ohio. For the past several decades, federal and state policy has incentivized a move toward more long-term supports and services provided in the community, rather than in institutional settings. Ohio spends more on long-term services and supports than the average U.S. state, but the average spending for home and community-based services in Ohio is less than half of the national average.

Long-term care

Before the passage of Medicare and Medicaid, care for the elderly was largely left up to the family, or to the individuals who purchased their own services. Medicare was the first governmental insurance program in the United States that guaranteed access to health insurance for individuals 65 years of age and older. Medicaid provides most of the funding associated with a nursing facility level of care. Currently in Ohio, more than two-thirds of all nursing facility services in Ohio are paid for by either Medicare (15 percent) or Medicaid (61 percent). The number of Americans who need long-term care is expected to double by 2050, while current national spending on long-term care services totals more than \$350 billion.

Over the past 15 years, Medicaid shifted from primarily funding long-term care in long-term care facilities to funding waivers that provide long-term care in home and community-based settings. The Ohio Department of Medicaid has aligned with the federal priority of balancing the number of older adults and adults with disabilities who receive care in the community and in long-term care facilities.

While the state has focused on increasing the quality of Nursing Facilities (NFs) through the reimbursement system, it has also enacted policies that continue to increase the number of individuals who receive services in the community. Costs for NFs are typically higher than for in-home care, which has an average cost of nearly \$60,000 a year. In addition, the Olmstead v. L.C. Supreme Court decision protects individuals against unnecessary institutionalization.

In the federal Deficit Reduction Act (DRA) of 2005, Congress established the Money Follows the Person (MFP) program. Ohio was one of 17 states that received funds to transition individuals in institutional settings like NFs into community-based settings, leading Ohio to create "HOME Choice." HOME Choice is a non-waiver program designed to help individuals of all ages move from a long-term facility to a community-based setting. As of 2016, nearly 8,500 people had taken advantage of HOME Choice, which is described in further detail below.

When Governor John Kasich took office in 2011, taxpayers spent 47 percent more on Medicaid longterm care than taxpayers in others states did. This included spending more Medicaid dollars on high-cost nursing homes and other institutions than 44 other states. To address this imbalance, the Governor's Office of Health Transformation (OHT) was created and made it a priority to direct Medicaid spending toward less expensive home and community-based long-term services. OHT did this by investing in the proliferation of Ohio's existing 1915(c) waivers that focused on the aging population. Waivers, as the name suggests, "waive" the requirement that a nursing facility level of care is provided in a facility to allow home and community-based settings to qualify for funding. The 1915(c) waiver name is a reference to the section of the federal law that deals specifically with home and community-based waiver services.⁴⁰

Currently, Ohio is deliberating "carving-in" the long-term care benefit for the elderly into managed care, which would mean that services for all Medicaid-eligible individuals in the long-term services and supports continuum would be overseen by a managed-care insurance company. There are 24 states that have implemented a managed long-term services and supports (MLTSS) benefit. The General Assembly delayed the implementation of this reform and it remains to be seen if the Governor Mike DeWine's administration will carry the effort forward.

Another change to the long-term care landscape will come from Medicare Advantage Plans. The federal Centers for Medicare and Medicaid Services (CMS) reinterpreted the definition of "primary health related" services that can be covered. Starting in 2019, Advantage Plans can opt to cover adult day services, home-based palliative care, in-home support services, support for caregivers of enrollees, stand-alone memory fitness benefit, home and bathroom safety devices and modifications, transportation and over-the-counter medications and equipment. Although Medicaid has covered many of these benefits in the past, this marks the first time Medicare will cover a number of these services.⁴¹ It remains to be seen how and to what extent these expanded services will be available through Advantage plans offered in Cleveland. This change has the potential to continue the trend toward greater support of Home and Community Based Services.

Determining community need for long-term care

Predicting who will need long-term services and supports is both art and science. Existing data sources can be used to consider the size of the aging population and the level of disability, and recent utilization rates can help predict future needs. However, the available data should not be relied upon as the sole predictor of future use of long-term care and it is not always available at smaller geographical levels. In an urban area that has a history of poverty and racial disparities, like Cleveland, it is also important to consider the non-health factors that may result in an earlier entry into, and heavier dependence on, the long-term care continuum's system of supports and services than would otherwise be predicted by health, age or disability. These things are often referred to as the social determinants of health and include economic stability, neighborhood and physical environment, education, food, community, social context and the health care system. These determinants have been shown to influence health outcomes including the need for long-term services and supports. Many of these topics are covered in the Age-Friendly Cleveland Assessment and are drawn upon to inform the scale needed for Cleveland's system of long-term care services and supports.

Current population

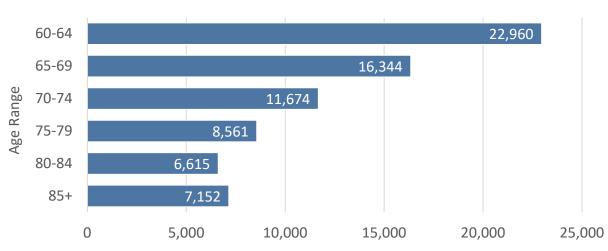
The City of Cleveland's population in 2016 was estimated to be 389,165, of which 18 percent were age 60 and older. While any individual of any age who lives in the city could need long-term care services and supports, older adults are more likely to access these services, and often need more services over time, although often not necessarily in a linear manner. The universe of long-term services and supports does not need to accommodate all 73,300 older adults of Cleveland at one time, however the Administration of Community Living, a division of the U.S. Department of Health and Human Services,

⁴⁰ "Home & Community-Based Services 1915(c)." Medicaid.gov.

https://www.medicaid.gov/medicaid/hcbs/authorities/1915-c/index.html

⁴¹ Medicare Drug & Health Plan Contract Administration Group Memorandum, April 27, 2018. https://www.nahc.org/wp-content/uploads/2018/05/HPMS-Memo-Primarily-Health-Related-4-27-18.pdf

estimates 69 percent of older adults will access some type of long-term care during the remaining years in their life with the level of care increasing with age.⁴²



Number of Older Adults in Cleveland by Age Range, 2016

A comparison of Ohio Medicaid-funded certified NFs and Assisted Living Waivers shows higher rates of older adults using long-term care. However younger adults also access these services. This information provides a sense of how many younger adults may enter the long-term care system at any given point in time. Approximately 16 percent of people who receive services at a certified NF and about 9 percent of those who access the Assisted Living Wavier are under age 60.⁴³

Disability prevalence

In addition to total population, rates of disability can be used to predict the community's need for longterm services and supports. The U.S. Census provides data on the prevalence of people with disabilities who live within the City of Cleveland in non-institutional settings. There are six categories on the American Community Survey related to disability; hearing, vision, cognitive, ambulatory, self-care and independent living difficulty, and people who have one or more difficulty are included in the disabled category.

Data Source: U.S. Census Bureau, American Community Survey 2016 5-Year Estimates

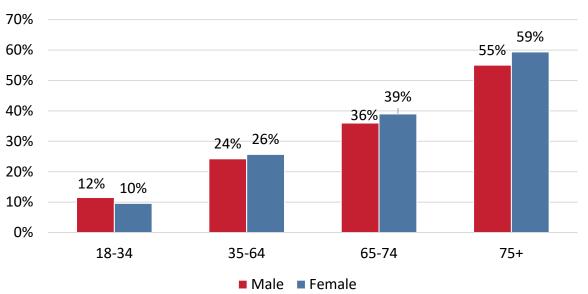
⁴² Distribution and duration of long-term care services. Retrieved on 10/29/2018 from <u>https://longtermcare.acl.gov/the-basics/how-much-care-will-you-need.html</u>

⁴³ Mehdizadeh, S., Nelson, M., Applebaum, R. Straker, J.K. (2017) Policy Does Matter: Continued progress in providing long-term services and supports for Ohio's older population. Scripps Gerontology Center of Miami University.

Difficulty	Census Definition
Hearing	Deaf or serious difficulty hearing
Vision	Blind or serious difficulty seeing even when wearing glasses
Cognitive	Serious difficulty concentrating, remember or making decisions due to a physical, mental or emotional condition
Ambulatory	Serious difficulty walking or climbing stairs
Self-Care	Difficulty dressing or bathing
Independent Living	Difficulty doing errands along such as visiting a doctor's office or shopping
Adult Disability	Ages 15 and older having any one of the six difficulty types

According to the report "Older Americans with a Disability: 2008-2012," 22 percent of older people with a disability have more than one disability.⁴⁴ This indicates a complexity in need that may require more than one intervention for an individual to maintain independence. National data from 2008 to 2012 shows a higher prevalence of disability among women, those aged 85 and over, people with less than a high school education, individuals who lost their spouse, people living alone or living in or near poverty. The study also found that black and Hispanic individuals with a disability had higher rates of poverty.

The most recent data available for disability type, living situation and poverty status in Cleveland can help project the number of older adults who will need supportive services as they age. According to the 2016 American Community Survey, 22.8 percent of the adult population in the City of Cleveland has a disability. This does not count individuals in nursing homes. In this group, a slightly higher percentage of females have a disability. As one would expect, the prevalence of disability increases with age.

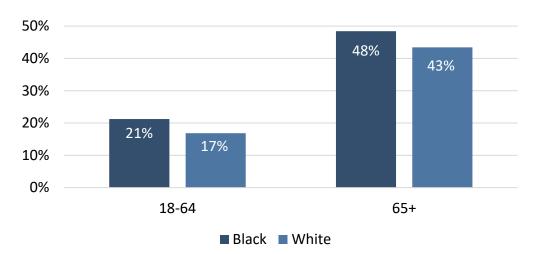


Cleveland Adult Population with a Disability, 2016

Data Source: U.S. Census Bureau, American Community Survey 2016 5-Year Estimates

⁴⁴ He, Wan and Luke J. Larsen, U.S. Census Bureau, American Community Survey Reports, ACS-29, Older Americans With a Disability: 2008–2012, U.S. Government Printing Office, Washington, DC, 2014.

In Cleveland, young adult males have a slightly higher rate of disability earlier in life, but that higher rate shifts to females beginning at age 35. The total number of older adults with a disability who live in the city is more than 22,000. One-in-four older adults with a disability in Cleveland live below poverty.



Cleveland Adult Population with a Disability by Race

Black residents of Cleveland have a higher rate of disability than white residents, both as younger adults and older adults, which mirrors national data. Forty-eight percent of black older adults have a disability compared to 44 percent of white older adults. Racial inequities have an impact on access to proper medical care and social supports throughout a lifetime which likely leads to a higher incidence of disability among people of color. Recognizing the higher prevalence among minority groups can help determine outreach and service strategies for specific populations.

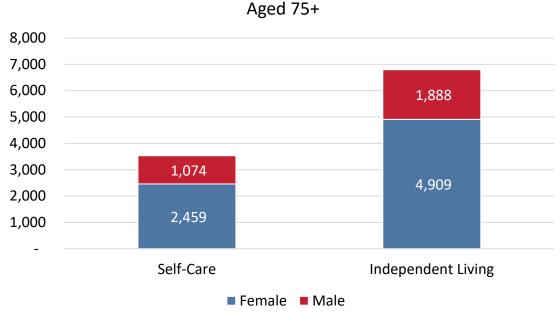
Among those ages 18 to 34, cognitive difficulty is the disability with the highest prevalence at 8 percent of the population or 7,654 individuals indicating difficulty. Many of these adults likely qualify for services through the Board of Developmental Disabilities. For those between the ages of 35 to 64, ambulatory difficulty occurs in 15 percent of the population, or 21,975 individuals. Those between the ages of 65 and 74 continue to have high rates of ambulatory difficulty and show an increase in independent living difficulty.

Age Range	Hearing		Vision		Cognitive				Self-Care		Indeper Livin	
	Pop.	%	Pop.	%	Рор.	%	Рор.	%	Рор.	%	Рор.	%
18-34	1,090	1.1%	1,109	1.20%	7,654	8%	1,676	2%	64	1%	3,460	4%
35-64	4,345	3.0%	6,028	4.20%	15,203	11%	21,975	15%	8,334	6%	15,002	10%
65-74	2,232	7.9%	1,907	6.70%	2,638	9%	8,513	30%	2,470	9%	4,480	16%
75+	4,468	19.8%	2,873	12.70%	2,972	13%	8,150	36%	3,735	17%	6,533	29%

Data Source: US Census Bureau, American Community Survey 2016 5-Year Estimates

Data Source: U.S. Census Bureau, American Community Survey 2016, 5-Year Estimates

Those older than age 75 see the most significant increase in hearing, self-care and independent living difficulties. Drilling down by gender in the oldest age group reveals that a larger number of females reside in the community and experience the type of difficulties that may necessitate long-term care services and supports. This is not surprising as women tend to have longer life expectancies than men.



Self Care and Independent Living Difficulty Cleveland, 2016

Data Source: U.S. Census Bureau, American Community Survey 2016 5-Year Estimates

Severe disability

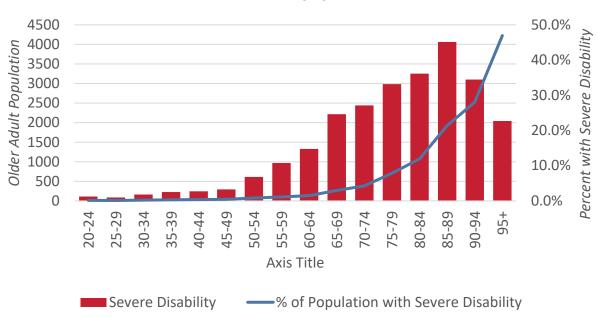
The Scripps Gerontology Center has projected the number of people living with severe and moderate disabilities for all of the counties in the state. For the purpose of these projections, the definition of severe disability is to "need the assistance of another person for at least two activities of daily living, or needing assistance with one activity of daily living and taking medication, or being cognitively impaired and requiring 24-hour supervision. Severe disability in this instance is matched with meeting Ohio's Medicaid Intermediate Level of Care, commonly known as nursing home level of care for those with physical and/or cognitive disability (OAC:101:3-3-06)."⁴⁵ Moderate disability is defined as requiring the assistance of another person to perform one ADL or having cognitive impairment requiring partial supervision. Both of these populations are likely to need long-term services and supports.

The share of older adults in Cuyahoga County with severe disabilities rises with age. Just more than 24,000 adults age 20 and older are projected to have a severe disability in the county in 2020. Another 14,500 are projected to have a moderate disability, so nearly 38,000 adults are projected to live with a disability in Cuyahoga County in 2020. Since 30 percent of the population of Cuyahoga County who is

⁴⁵ Mehdizadeh, S. Kunkel, S. (2014). Projections of Ohio's Population with Physical and/or Cognitive Disability by County, 2010-2030. Scripps Gerontology Center, Miami University, Oxford, OH.

age 20 or older lives in the City of Cleveland, between 11,000 and 12,000 people who are projected to have a disability may reside in the city.

Of those aged 65 and older, 3.1 percent, or 7,000 people in the county, are projected to have a severe disability and income under 200 percent of the federal poverty level. These individuals will likely qualify for Medicaid to cover long-term care services and supports. The remaining 13,000 who have a severe disability may also qualify for Medicaid, but may need to spend down their assets and set up a trust for any income above the Medicaid eligibility threshold. Those who do not, and will not, qualify for Medicaid will need to use private resources for their long-term care.



Projected Prevelance of Severe Disability in Cuyahoga County 2020

Data Source: Scripps Gerontology Center

Social determinants of health

In addition to disability, individuals often need long-term services and supports earlier when they have faced challenges with the social determinants of health. The World Health Organization defines social determinants of health as "the conditions in which people are born, grow, live, work and age and the wider set of forces and systems shaping the conditions of daily life."⁴⁶ The Kaiser Family Foundation includes economic stability, neighborhood and physical environment, education, food, community and social context and the health care system as social determinants of health.⁴⁷

Older adults in Cleveland who have experienced negative social determinants of health are more likely to experience adverse health outcomes that result in the need for more long-term care supports. Based on survey data from older adults who live in Cleveland, estimates can be calculated for those impacted

⁴⁶ <u>https://www.who.int/social_determinants/en/</u>

⁴⁷ Samantha Artiga, S. Hinton, E. (2018) Beyond Health Care: The Role of Social Determinants in Promoting Health and Health Equity. Kaiser Family Foundation. Issue Brief. <u>https://www.kff.org/disparities-policy/issue-brief/beyond-health-care-the-role-of-social-determinants-in-promoting-health-and-health-equity/</u>

by specific social determinants of health. A more detailed analysis of the data can be found in the Appendix, and key points are outlined here:

- The median income for a head of household, who is age 65 or older, in the City of Cleveland is \$22,736. This is less than 200 percent of the federal poverty level for a family of any size. Since so many of Cleveland's older adults have low incomes, economic stability is a challenge.
- In terms of the neighborhood and physical environment, 60 percent of older adults in the Age-Friendly Cleveland assessment indicated that sidewalks in their neighborhoods were uneven and unsafe, which directly impacts walkability. More than one-third said that their neighborhood does not make them feel safe and protected, and nearly one-quarter feared they would be a victim of crime in their neighborhood. In addition to influencing health, this could mean that some neighborhoods in Cleveland are less suitable for older adults to age in place.
- Level of education has an impact on health, and studies have shown that those with a bachelor's degree or higher have better health outcomes. Amongst Cleveland's older adults, just 11 percent have attained a bachelor's degree or higher. This means 89 percent of older adults have not reached a level of education associated with more positive health outcomes, including lower rates of chronic disease and increased life expectancy.
- Fifty-two percent of Cleveland's older adults do not feel connected to their communities and approximately 40 percent rarely or never participate in social or community events. Coupled with the fact that the U.S. Census Bureau estimates that more than 20,000 older adults in Cleveland live alone, social isolation may be more prevalent in Cleveland.
- Discrimination can reduce connection to community and lead to social isolation. Fifty-nine percent of older adults in Cleveland agreed with the statement, *"There are negative stereotypes about older adults."* Just 46 percent of respondents to the Age-Friendly Cleveland assessment survey agreed that older people are valued in the community.
- Cleveland has a long history of residential racial segregation and remains highly segregated. As multiple studies have demonstrated, residential racial segregation leads to health disparities and poorer outcomes for communities of color. Maps of racial distribution in Cleveland compared to health outcome maps show a clear pattern of poor health outcomes in areas with higher concentrations of African-Americans.
- Lack of access to proper nutrition over the course of a lifetime plays a role in the health outcomes of older adults. Even with a well-developed network of food support within the city, 25 percent of older adults do not, or are not sure if they have access to healthy affordable food within their own neighborhood. This translates to more than 18,000 older adults in Cleveland.
- At lower levels of care, housing stock is an additional challenge for Cleveland residents seeking to age in place. Houses built prior to the 1950s often lack accessible features. Cleveland houses tend to have steps, even to enter the home, small doorways, no first floor bathrooms and the kitchen and bedrooms on different levels. Many Cleveland neighborhoods lack walkability and public transportation, which means people may choose to move out of their homes before they would like to.

Adverse experiences related to these social determinants can lead to poor health outcomes, which increases the likelihood an older adult will need long-term services and supports. We can assume a higher percentage of older adults who live in Cleveland will need to access these services compared to their peers who live in communities who do not have these challenges to the social determinants of health.

Need and capacity

Given the complexity of the long-term care system and the fact that good data on utilization exists for only a portion of the continuum, it is extremely difficult to estimate the number of Cleveland residents in need of long-term care services and supports, both now and in the future. Factors that influence the number of people in Cleveland who need long-term care include:

- Thirty one percent of older adults in Cleveland are over the age 75.
- More than 10,000 older adults in Cleveland have a self-care or independent living disability.
- Around 40 percent of those older than age 75 have a severe disability.
- Most older adults in Cleveland are at risk of having negative health outcomes as a result of one or more social determinants of health.
- More than half of Americans older than age 65 are likely to need for long-term services and supports for at least a year.⁴⁸

National studies estimate that the number of Americans who use paid long-term care will double by 2050, growing to 27 million people.⁴⁹ Another study estimated that there is a 68 percent chance that a person aged 65 or older will need long-term care because they have become disabled and not able to perform at least two activities of daily living or they will be cognitively impaired.⁵⁰ In Cleveland, that would be around 35,000 people – although they will not all need the same level of care at the same time. Close to 8.5 million people in the United States access long-term care each year from five main sources: home health agencies, nursing homes, hospice, residential care and adult day centers, of which 6.3 million rely on home and community based services.⁵¹ That is around 2 percent of the total population. Many more receive informal care from family and friends.

Using national estimates from several sources and U.S. Census Bureau data, Community Solutions calculated that somewhere between 9,000 and 15,000 of Cleveland's older adults need long-term care each year. This number is expected to increase as people live longer and as the population continues to age. Since so many Clevelanders have negatively experienced social determinants of health, it is likely that they will need higher levels of care at earlier ages than residents in other parts of the country where social determinants are more in their favor.

The capacity for long-term care services can be estimated from the four main delivery methods of longterm care; PACE, Assisted Living, Nursing Facilities and HCBS Waivers. Within the waiver and PACE methods a number of services are provided including adult daycare, in home health care, homemaker and meal services, among others.

 ⁴⁸ Favreault, M., Dey, J. (2016) Long-term services and supports for older Americans: risks and financing research brief.
 Office of the Assistant Secretary for Planning and Evaluation, US Department of Health and Human Services
 ⁴⁹ U.S. Department of Health and Human Services, and U.S. Department of Labor. The future supply of long-term care workers in relation to the aging baby boom generation: Report to Congress. Washington, DC: Office of the Assistant Secretary for Planning and Evaluation, (2003).

⁵⁰ AARP. Beyond 50.2003: A Report to the Nation on Independent Living and Disability, 2003.

⁵¹ Harris-Kojetin L, Sengupta M, Lendon JP, Rome V, Valverde R, Caffrey C. Long-term care providers and services users in the United States, 2015–2016. National Center for Health Statistics. Vital Health Stat 3(43). 2019.

Long-Term Care Delivery Method	Cleveland Capacity
PACE	400
Assisted Living	480
Nursing Facilities	2,833
HCBS Waivers	6,550
Total	9,915

The capacity of these sources is highly regulated and meant to match need. Even if there are enough total beds, it is not clear that the mix of levels of care is appropriate to match community need, whether there is availability with high-quality providers, or if people are able to receive services from the provider of their choice. Key informants pointed to concerns about the difficulty faced by Cleveland residents to access assisted living services, especially for people of color and for those who have lower incomes. It is also unclear how many people who privately pay are served, and whether capacity is sufficient to meet their needs.

While it appears that there is a sufficient number of total slots for long-term care in Cleveland, it is unlikely that this represents the appropriate mix of settings. At higher levels of need, there seems to be enough nursing beds and we did not find evidence of waiting lists for Medicaid waivers. However, navigation services are lacking, which results in a lack of information and understanding among residents, as indicated in the Age-Friendly Cleveland assessment report.

Ability to pay for long-term care

Even if there is sufficient capacity in the system, paying for long-term care will be challenging for many Cleveland residents. Low-income residents can be covered by Medicaid and those with higher incomes can afford to privately pay. However, those with moderate levels of income and savings make too much to qualify for assistance, but too little to privately pay for long-term care.

The fact that Cleveland is a high-poverty city presents issues for the long-term care continuum because fewer people are able to privately pay. The high cost of long-term care services, and lack of planning by residents, could contribute to generational poverty, as savings and assets must be used before someone can access Medicaid coverage.

When an individual's health meets the level of care to be eligible to receive care through a long-term care or a skilled NF, many Cleveland residents are faced with the reality of paying for care, either out of pocket or through government assistance programs. Often family members are also involved in the decision on how and where the individual receives care. There are essentially three options available to Cleveland's older adults to cover the cost of long-term care: accessing Medicaid, privately paying or using long-term care insurance.

Cost of care

The cost of long-term care is very individualized, particularly in home and community-based settings. Depending on the individual need and access to unpaid caregivers, an individual will purchase various services. The Genworth 2017 Cost of Care estimates the cost for homemaker health care, adult daycare, assisted living facility and nursing home care for U.S. Metropolitan Statistical Areas including Cleveland. Estimates were calculated for each region based on surveys and interviews of administrators of the various agencies that provide care.⁵² The table below details the 2017 daily cost estimates for care in Cleveland.

Cleveland Cost of Long-term Care Services							
Daily Monthly Annual							
Service	Cost	Cost	Cost				
Adult Day Health Care	\$57	\$1,235	\$14,820				
Assisted Living Facility	\$111	\$3,375	\$40,500				
Homemaker Services	\$135	\$4,099	\$49,192				
Homemaker Health Aide	\$138	\$4,195	\$50 <i>,</i> 336				
Nursing Home - Semi Private room	\$233	\$7,072	\$84,863				
Nursing Home - Private Room	\$268	\$8,159	\$97,911				

Data Source: Genworth Cost of Care Survey

The daily rate for homemaking services is based on 6.25 hours of care per day. Adult daycare typically covers six to eight hours of the day and the assisted living facility rate is based on a private, one-bedroom unit.

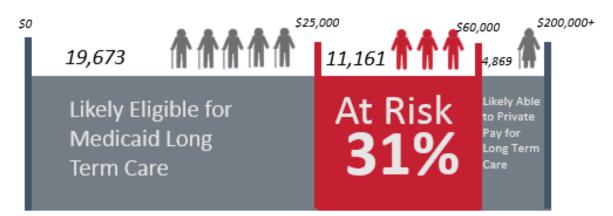
Community Solutions developed a model to estimate the number of older adults in the community who are likely to be covered by Medicaid, able to privately pay and those who are at risk of not being able to afford long-term care. The methodology is described in detail in the Appendix. As the model demonstrates, there are situations when the level of care and type of service cannot be covered by the individual's income alone. The group that experiences the most financial struggle is the group who doesn't financially qualify for Medicaid but is below an income that could support privately paying for services.

⁵² Genworth Cost of Care Survey 2017, Methodology



Nearly 1 in 3 Cleveland Older adults are at risk of not being able to afford long term care services and supports

Income of Cleveland Older Adults (65+)



In Cleveland, there are approximately 11,000 senior households with incomes in the 'at-risk' zone of between \$25,000 and \$60,000. This represents more than 30 percent of the older adult population. The financial and emotional weight of needing skilled care goes beyond the individual, and impacts family and nonprofessional caregivers. Family members and other loved ones often cover the gap between what the individual needs and what the individual can afford. This comes both in the form of the physical act of caregiving, and contributing financially to the cost of care. Therefore, even if suitable long-term care supports and services are available, older adults in Cleveland may find cost a significant barrier to access.

Recommendations

There are several things that could strengthen the long-term care continuum in Cleveland.

• There is a need for increased understanding of aging among the general population to prepare for both caregiving and aging. Former First Lady Roslyn Carter observed, "There are only four kinds of people in the world. Those who have been caregivers. Those who are currently caregivers. Those who will be caregivers, and those who will need a caregiver." While long-term care is something that most people will encounter in their lives, either for themselves or a loved one, long-term care planning is uncommon. Decisions about long-term care are often made in times of crisis, when the older adults has experienced a health event that requires an immediate change in living situation. Many older adults in Cleveland identified stigma associated with growing older which could prevent families from having open discussions about long-term care options before they are needed.

Informed decisions about long-term care are particularly challenging because of a dearth of readily accessible information. Although the best information is about agencies, services and supports that are regulated by government, it is still scattered. Comprehensive information about long-term care services available in a community do not exist. Developing resources for the general public and sharing information about preparing to age-in-place could help.

- Family caregivers are a critical component of the long-term care continuum, but one that is often overlooked. Many family caregivers reported experiencing challenges balancing paid employment and unpaid caregiving responsibilities, which can threaten a caregiver's income at a time when financial resources are more important. Age-Friendly Cleveland or its partners should create **a resource for caregivers to utilize in discussions with their employers about caregiving responsibilities**. This must include information about family caregiving covered by the Family and Medical Leave Act. Policies that are favorable for family caregivers should be considered when providing the Age-Friendly business designation.
- The Western Reserve Area Agency on Aging and Cleveland Department of Aging have resources available to provide support for family caregivers. **Investment in programs and services for unpaid caregivers should be maintained or increased**. A full suite of supports would include training, education, stipends and respite services.
- Transitions are particularly difficult for older adults and their caregivers as these represent a time of upheaval, however resources that support transitions are lacking. Resource programs that provide transition management services including case coordination, case management and options counseling would strengthen this part of the long-term care continuum.
- Personal safety is of paramount concern as people age in place. However, most homes in Cleveland did not have age-friendly features when they were built. Efforts are underway under the Age-Friendly Cleveland umbrella to increase things like fall prevention activities for older adults, which includes information on improving safety and reducing fall risks in homes. Data shows that as age increases, so does the likelihood that a person will experience mobility challenges. This will require home modification. **Developing additional resources to provide home modifications will allow older adults to safely age in place.** Remaining at home and in the community is the preference of most older adults in Cleveland and is a less expensive alternative to full-time care in a long-term care facility.
- Cleveland is a high-poverty city, and many older adults and their families do not have the financial resources to pay for long-term care services. Medicaid is a vital source of health coverage for low-income older adults that pays for a substantial share of long-term care services in Cleveland. Close to one-third of Cleveland's older adults have too much income to be eligible for Medicaid, yet not enough to be able to pay privately. For these older adults with moderate incomes, subsidy or sliding fee scale programs could be developed so that they can access services they otherwise would not quality for nor would they be able to private pay.

Conclusion and key findings

The long-term care continuum is a vital component of an Age Friendly community. However, there is no consistent definition of what constitutes long-term care, or the components and features that comprise the continuum. We include hospital stays, family caregiving, home care, rehabilitation facilities, Medicaid waivers for home and community based services, adult day services, nursing facilities, transition and case management, palliative and hospice care in our examination of Cleveland's long-term care system. Long-term care can be provided in a variety of settings, at any age, to those with or without disability who need differing levels of care, so additional supports, such as transportation, may be needed. The trend toward aging in place, with more services available to individuals who reside in the community, rather than aging in an institutional facility, has been positive for many older adults. However, it makes understanding the breadth and depth of long-term care in Cleveland more difficult, because fewer regulations apply to community-based services, especially those for which people privately pay.

The Age-Friendly Cleveland advisory committee identified several criteria for a high-quality long-term care system. One of these is that long-term services and supports should be client-centered, another is that the dignity of the individual should be prioritized and, when possible, older adults should be provided with choices about how to maintain independence. Unfortunately, it is impossible to ascertain from existing information whether Cleveland's current long-term care services and supports meet the criteria with any certainty. Information gathered from older adults during the Age-Friendly Cleveland assessment and via key informant interviews indicates that more planning, care coordination and options counseling are needed to ensure that individuals receive the appropriate level of care through transitions. Strong support systems, case management and prevention through education and resources can reduce or delay the need for more intensive services and supports.

Family caregiving is a key part of the long-term care continuum, but one which is exceedingly difficult to quantify for smaller geographies. Providing care for a loved one is a role that often comes with little to no training or preparation, and many people enter the long-term care system after a crisis. Individuals and family members are suddenly forced to navigate a multifaceted system of agencies, both public and private, and to coordinate the care necessary to meet needs in a way that is affordable and safe. It was even difficult for researchers from Community Solutions, who are already familiar with many of the agencies that comprise the network of senior services, to find information about the number of long-term care providers operating in the City of Cleveland at various points on the continuum. Some providers, especially those that are for-profit, have no incentive to provide utilization or cost information beyond their marketing efforts. Information for publically-funded services, such as Medicaid or Medicare fee-for-service, were much more readily available. Even after months of research, the total capacity of home care agencies working with clients in Cleveland is not clear, and we are forced to assume that it will be economically advantageous for companies to meet market demands. Quality remains an open question.

Where better data was available, we found that assisted living and nursing home facilities tend to be clustered in a few areas within the City of Cleveland. Therefore, older adults in other parts of the city with higher needs will be forced to leave the neighborhoods they call home in order to find appropriate levels of care. Similar to the rest of the state, 40 percent of nursing homes in Cleveland were below average in overall quality rating, and only four facilities achieved the overall highest score of five stars.

A common concern among older adults, caregivers and key informants is frustration with the lack of information and knowledge about long-term care. Many older adults and their family caregivers are not

well-informed about long-term care options, and conducting research for this report showed how difficult it is to access consistent information about services provided, cost, capacity and utilization. More than half of Cleveland's older adults said they were unsure if they could find a suitable provider if health or mobility issues forced them to move out of their homes or neighborhoods. Since most Americans will need long-term care during their lives, or will help a loved one navigate their long-term care needs, a better understanding of what the various parts of the long-term care continuum are, do and cost could reduce stress, improve health outcomes and lower the need for more costly levels of care. Similarly, many providers in the aging network report an increasing number of older adults who would benefit from care coordination and case management, but either do not qualify or do not know how to access it. An area of opportunity for the city, nonprofits associated with the aging network and private sector organizations serving seniors is aging literacy.

At higher levels of care, it appears that capacity is sufficient to match need. This is not surprising since these services, especially nursing beds, are highly regulated. Up to 15,000 residents of Cleveland require long-term care services each year. National studies suggest that around 20 percent of those who need long-term care do not receive it. Even so, there appears to be enough capacity in Cleveland's long-term care system overall, but perhaps not the right balance. Choice and quality are of particular concern.

Cost, to individuals, families and to public systems, has been a driving factor in the development of the long-term care continuum. Public policy decisions have underpinned the shift from institution-based to home and community-based care over the past several decades. In high poverty areas, such as Cleveland, Medicaid is an important source of long-term care for older adults, and more Clevelanders are likely to qualify for Medicaid services and supports than in other communities in Northeast Ohio. However, 31 percent of older adults in Cleveland are at risk of not being able to afford long-term care, because they earn too much to qualify for Medicaid but too little to likely be able to privately pay.

Finally, the need for long-term care in Cleveland could be greater than in other parts of the country because many older adults in Cleveland have negatively experienced social determinants of health, which could mean that they will need higher levels of care at earlier ages. Cleveland's housing stock is older, most homes do not contain age-friendly features and are not appropriate for individuals with less mobility. Few residences in Cleveland have bedroom, bathroom and kitchen facilities on the same floor, external maintenance was also identified as a particular challenge by older adults in Cleveland in the Age-Friendly Cleveland assessment, and many pointed to safety as a concern, relating to both sidewalks and crime.

The vast majority of older adults in Cleveland wish to remain in their neighborhoods as they age, and the trend has been for more long-term care services to be provided in the community. However, there are serious concerns about whether individuals and providers across the continuum are prepared to meet that demand appropriately. Overall, our research indicates that Cleveland residents in certain parts of the city will be forced to move out of their neighborhoods in order to find appropriate and affordable long-term care as their needs increase.

Appendix I: Illustrative examples

The following case studies further illustrate key aspects of the long-term care continuum. While loosely based on real situations, they are intended to mirror the lived experiences of residents in Cleveland. This includes the non-linear nature of long-term care needs, with transitions in and out of facilities to meet varying levels of care. As described in the narrative below, some older adults navigate the long-term care system alone, while others rely on substantial support from family members.

Case study: Wanda

Wanda is a 79-year-old, African-American woman born and raised in Cleveland. Wanda grew up in a segregated neighborhood of Cleveland called Hough. Her parents worked hard to provide for her and her four siblings, but the family often faced food insecurity. As an African-American female, she faced countless instances of discrimination throughout her life. She finished school reading at a 5th grade level. She entered the workforce at the age of 16 as a hotel maid.

Food insecurity is social determinant of health that can impact outcomes at any age. p. 31

Throughout her life, Wanda had intermittent contact with health care services. The poor medical treatment she received as a child caused her to be distrustful of the health care system. Wanda typically missed doctor's appointments, especially since she began living on her own. Her income and resource level qualify her for Medicaid and she is currently enrolled in a MyCareOhio plan that combines her Medicaid and Medicare coverage. Generally, Wanda was fearful to leave her home and never felt truly safe in her neighborhood, creating yet another barrier to care.

Although she experienced years of emotional distress and difficulty in relationships, Wanda did not seek mental health treatment until well into her 40s. A mental health provider diagnosed her with Bipolar II disorder at the age of 46. Her mental health struggles caused rifts with her family members and she is estranged from them.

Wanda was never married and does not have any children. All of her siblings, nieces and nephews still live in the Cleveland area, but she is not in contact with them. Wanda continued to live in the Hough neighborhood in the home she grew up in. Her brother inherited the home when her parents passed away, and she lived there with him until he moved into a nursing home. She began living there alone in 2010. Wanda's brother passed away in 2014 and named her as the beneficiary of his life insurance policy, which put her over the asset limit for Medicaid. Fortunately she was able to work with Legal Aid to develop a plan to spend down the inheritance.

Social and familial isolation increases risk of self-neglect. p. 47 Wanda fell in her home in 2016. When EMS arrived, they had difficulty entering the home because of clutter blocking the entrance. Once inside, they found Wanda's home in complete disarray. There were piles of clutter in every room, and it was discovered that approximately 10 cats lived in the home. The responders found Wanda extremely despondent and she struggled to answer their questions clearly or make direct eye contact. Wanda's fall caused her to break her hip. She had major surgery and spent one week in the hospital recovering.

After her week in the hospital, Wanda was referred to a skilled nursing facility by her doctors. Wanda struggled to adjust to these arrangements, but her injury caused impairment in four major activities of daily living. She was unable to bathe, dress, use the toilet or get out of bed on her own. Wanda often felt dismissed by the staff at the nursing facility. She would press her call button for assistance multiple times before getting a response. On one

occasion, she waited two hours before someone finally came to her room. Additionally, nurses would come into the room and fail to explain the purpose for procedures being done. Wanda felt she did not have any choice in her care. Three weeks into her stay, Wanda recovered some and became more mobile. Since she was able to walk, she decided it was time to leave. Her doctors felt otherwise, but she said she couldn't stand one more day in the facility. She had the front desk call a cab for her and left the facility without her medications.

When she arrived at her home, the electricity, gas and water were turned off. Wanda recalled a number the emergency department social worker gave her for the Department of Aging and gave them a call. She told the representative that her utilities had been shut off and she does not have her medications. The representative probed more and discovered that Wanda had left against her doctor's wishes. The representative also listened to Wanda's complaints about her

care. Two calls were made after the representative spoke with Wanda. First, transportation was arranged to get Wanda back to the nursing facility to ensure she was safe. Then, a call was made to the Long-Term Care Ombudsman to report Wanda's complaints.

Wanda was moved from the nursing facility to a comprehensive outpatient rehabilitation facility to continue to increase her strength and functionality. During her stay, she reached out to the Department of Aging to seek assistance to plan for her return home. Although Wanda preferred to stay in her home, she agreed with the long-term options counselor that she was no longer able to keep up with the maintenance. The worker provided Wanda with a list of apartments, and after calling around Wanda was able to find a unit in a subsidized senior building.

Supportive services provided by local agencies play a role in keeping older adults safe in their homes p. 11

The average length of stay at a skilled nursing facility in Cleveland is 25 days. p. 18

A hospital stay is often the entry point into long term care services and supports. p. 7 As she transitioned back to the community, the care manager of her MyCareOhio plan helped her set up in-home services. Through this program, Wanda receives home-delivered meals, non-medical transportation, mental health counseling and adult daycare. Wanda resisted the adult daycare center at first. Her years of isolation caused her to be weary of social gatherings and she was self-conscious about her mental illness. After many weekly sessions with her counselor, Wanda

Adult Day services provide social and medical services. p. 15

warmed to the idea of going twice a week. At the daycare center, she got involved in arts and crafts and enjoyed the meals that the center provided. Soon two times per week became three and then four times per week. Wanda's counselor notes marked improvement in Wanda's mood and energy levels. Wanda herself reports this is the happiest she's been in more than 40 years.

Case study: Earl

Earl is an 82-year-old, retired, white male. When Earl was young, his family migrated from West Virginia to southern Ohio. Earl moved to Cleveland 45 years ago for a job at a steel mill. Earl lost his wife eight years ago and lived alone in the home they owned together until spring of 2015. He has three adult children. His son John lives in the Cleveland area with his wife, Rita. The couple has two college-aged children. His daughter Rachel is single and lives in Chicago. And his youngest daughter, Julie, lives with her husband and teenage daughter in Columbus. Earl also has relatives in West Virginia and Southern Ohio.

Prevalence of disability increases with age. p. 27 As he has aged in his community, Earl noticed there were fewer and fewer places he can walk to in his neighborhood. He stopped driving a year ago and relies on his once-weekly opportunity to use Senior Transportation Connection to run errands. He tried to use public transportation but the closest stop to his house is a half-mile away and the sidewalks along the route are uneven. He worried about falling.

In the winter of 2014, Earl's son John noticed that his dad was becoming increasingly forgetful. He struggled to remember the names of his grandkids and seemed to always ask the same few questions over and over again. Weary of an extensive family history of dementia and Alzheimer's disease, John encouraged his father to see his doctor. Earl resisted. He already had \$15,000 worth of medical debt from back surgery.

Medical debt impacts the financial and physical well-being of older adults p. 44 The following summer, John visited his father's home and saw an unkempt yard. This was uncharacteristic as yard work was one of Earl's favorite pastimes. When John asked about it, Earl admitted that he couldn't figure out how to turn the lawnmower on. John insisted that his dad see a doctor and scheduled the appointment for him. As John had suspected, the doctor diagnosed Earl with Stage 2 Alzheimer's disease. John and Rita decided that Rita would take on the responsibility of caring for Earl. She cleaned the house, did the grocery shopping, prepared meals, and organized and administered medications. One day, Rita came to care for Earl and found him in distress because he could not find his favorite mug. As Rita attempted to help Earl find it, he became increasingly irritable. Rita and Earl were very close, and she had never seen him like this. She was upset and called John in tears over the ordeal. They called the Alzheimer's Association and the Cleveland Department of Aging for support. Through these

Many families with limited financial resources rely on family caregivers. p. 9

Hospice care allows an individual to maintain comfort during illness. p. 22 organizations, the family was able to delay the need for facilitylevel care for Earl. John and Rita worked with the city to modify Earl's home to fit his needs. Leaf pickup was arranged and food delivery was coordinated for the days that Rita was not available. On top of these supports, John and Rita started attending Alzheimer support groups to help cope with caring for a loved one with the disease.

The disease progressed much faster than they anticipated. Earl was admitted to the Hospice of the Western Reserve after a decline. John and Rita, along with Earl's other two children, met with Earl's team including a physician, a registered nurse, a social worker, a member of the clergy and a volunteer. The family had difficulty accepting that Earl needed this level of care. This meeting proved beneficial and the family felt supported by Earl's team of health care providers. John and

Rita continued to take the lead on Earl's care, and the team of providers allowed the couple to be involved in every decision. Earl passed away peacefully.

Appendix II: Social Determinants of Health

In addition to disability, individuals often need long-term services and supports earlier when social determinants of health are not in their favor. The World Health Organization defines social determinants of health as "the conditions in which people are born, grow, live, work and age and the wider set of forces and systems shaping the conditions of daily life."⁵³ The chart below included in an issue brief produced by the Kaiser Family Foundation provides an explanation of the individual factors that make up the social determinants of health.⁵⁴

Fiaure 1

Social Determinants of Health

Economic Stability	Neighborhood and Physical Environment	Education	Food	Community and Social Context	Health Care System		
Employment Income Expenses Debt Medical bills Support	Housing Transportation Safety Parks Playgrounds Walkability Zip code / geography	Literacy Language Early childhood education Vocational training Higher education	Hunger Access to healthy options	Social integration Support systems Community engagement Discrimination Stress	Health coverage Provider availability Provider linguistic and cultural competency Quality of care		
Health Outcomes Mortality, Morbidity, Life Expectancy, Health Care Expenditures, Health Status, Functional Limitations							



Older adults in Cleveland who experience negative social determinants of health are more likely to experience adverse health outcomes that result in a need for more long-term care supports. Data from the Age-Friendly Cleveland Assessment and other data sources can provide context for how prevalent of the social and environmental issues that result in negative health outcomes are.

Economic Stability

The economic stability of an older adult depends on multiple factors related to their finances including employment, income, expenses, debt, medical bills and support. Lack of economic stability can lead to

⁵³ <u>https://www.who.int/social_determinants/en/</u>

⁵⁴ Samantha Artiga, S. Hinton, E. (2018) Beyond Health Care: The Role of Social Determinants in Promoting Health and Health Equity. Kaiser Family Foundation. Issue Brief. <u>https://www.kff.org/disparities-policy/issue-brief/beyond-health-care-the-role-of-social-determinants-in-promoting-health-and-health-equity/</u>

conditions that directly impact health such as inability to afford basic needs, high levels of stress and inability to maintain housing. The median income for the head of a household older than 65 in the City of Cleveland is \$22,736, which is less than 200 percent of the federal poverty level. While 43 percent of older adults in the 60 to 64 years old age range are in the labor force, the percentage drops to 18 percent for those aged 65 to 74 and 5 percent for those older than age 75. As labor force rates drop, the reliance on Social Security and or state retirement programs as a sole source of income increases.⁵⁵

The Elder Index, developed by the Institute for Women's Policy Research and the University of Massachusetts Boston, calculates a single older adult living in Cuyahoga County has annual expenses of \$20,148 if they own a home and do not have a mortgage, \$21,504 if they rent and \$28,164 if they own a home with a mortgage. These expenses include housing, food, transportation, health care and other miscellaneous categories. This budget does not include expenses related to debt management, home repair/modification or long-term care supports.⁵⁶ Average expenses and income in Cleveland are very close together, leaving little room for needs not included in a basic needs budget.

In addition to basic needs, an increasing number of older adults also must budget for monthly debt payments. A national study conducted by the Employment Benefit Research Institute found that the percentage of American families with debt in households headed by someone aged 55 or older has risen. For a family that has debt and a yearly income between \$25,000 and \$49,000, the median debt is \$29,000. In families where the head of household is older than age 55 and retired, the median debt is \$25,000.⁵⁷ Medical debt is higher and more prevalent among African-Americans compared to their white peers.⁵⁸ According to the National Center on Law and Elder Rights, 20 percent of older adults have at least one medical debt collection on their credit report.⁵⁹ Older adults who are in debt engage in behaviors that could lead to poor health outcomes including cutting pills, avoiding social engagements, skipping medical appointments and skipping meals.⁶⁰

Medical bills, when unpaid, turn into medical debt and while 20 percent of older adults nationally have medical debt, according the Age-Friendly Cleveland assessment, 45 percent of older adults in Cleveland struggle to afford medical bills at least some of the time and 35 percent have difficulties affording medication.

A number of factors can indicate economic instability among older adults that may be a predictor of earlier entry and longer use of long-term services and supports. Those who appear to be at a higher risk in Cleveland are those who have incomes that do not match their expenses, and those with levels of debt beyond their ability to repay without sacrificing basic needs.

⁵⁵ US Census American Community Survey 2016 Five Year Estimates

⁵⁶ <u>http://www.basiceconomicsecurity.org/El/location.aspx</u>

⁵⁷ Copeland, Craig. Debt of the Elderly and Near Elderly, 1992-2016. Employee Benefit Research Institute, Issue Brief. March 5, 2018 (443).

⁵⁸ Wiltshire, J. C., Elder, K., Kiefe, C., & Allison, J. J. (2016). Medical Debt and Related Financial Consequences Among Older African American and White Adults. American journal of public health, 106(6), 1086-91.

⁵⁹ Bosco, J. (2017) Medical Debt Strategies for Older Consumers. Issue Brief National Center on Law & Elder Rights 60 NCOA Older Adults and Debt: Trends, Trade-offs, and Tools to Help. <u>https://www.ncoa.org/wp-</u> content/uploads/NCOA-Older-Adult-Issue-Debt-Brief.pdf

According to the U.S. Census, about 30,000 heads of households age 60 or older own a home, and about 20,000 householders aged 60 or older rent.⁶¹ With the estimated budget for older adults ranging from \$20,000-28,000, the median income for older adults in Cleveland at just more than \$22,500 and the increasing prevalence of debt and medical debt, it is reasonable to believe that older adults in Cleveland who have incomes below \$30,000 are impacted by the social determinant of economic stability.

Neighborhood and Physical Environment

Reliable, affordable transportation is critical to health outcomes. According to the Age-Friendly Cleveland Assessment, 32 percent of older adults do not drive themselves to appointments, errands, events or community locations. This segment of older adults uses alternative modes of transportation, primarily relying on friends and family, taking public transportation, walking and using senior transportation services. Those aged 75 and above are even less likely to drive themselves with 43 percent relying on modes of transportation other than driving themselves. Twenty-three percent of older adults have some difficulty getting around, regardless of preferred mode of transportation, with nearly 20 percent reporting they do not feel safe walking where they need to go. Lack of reliable, safe transportation is a social determinant that has been shown to lead to poor health outcomes.⁶²

More than 60 percent of older adults who responded to the Age-Friendly Cleveland Assessment indicated that sidewalks in their neighborhoods are uneven and unsafe, which directly impacts the walkability of the older adults' immediate environment. It also impacts their ability to access public transportation, as multiple blocks of unsafe sidewalks can be impossible for an individual with a mobility impairment to traverse.

Safety is a concern for some older adults who live in Cleveland, with 16 percent not agreeing with the statement *"I feel safe in my home"* and 23 percent fearing they will be a victim of crime in their neighborhood. While 65 percent feel safe and protected by their neighbors or neighborhood, 35 percent do not.

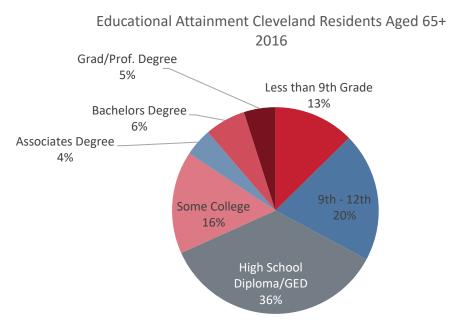
Both housing affordability and the ability to maintain housing present challenges to older adults who live in the city. Sixteen percent do not agree with the statement, "I am able to afford my current housing" and 18 percent do not agree that they can afford utilities. Only 50 percent of older adults in Cleveland report being able to maintain the outside of their homes and just 42 percent plan to make home modifications to adapt to their needs as they age.

Lack of stability in the physical environment can lead to a direct health impact on older adults such as falls, as well as indirect impacts including high levels of stress and anxiety that contribute negatively to chronic health conditions.

⁶¹ The estimates are based on "householders" and do not include all community living older adults in the city. 62 Anthes, Loren. "From Point A to Point B: Transportation as a Social Determinant in Medicaid" the Center for Community Solutions. October 2018. <u>https://www.communitysolutions.com/research/point-point-b-transportation-social-determinant-medicaid/</u>

Education

Level of education has an impact on health, and studies have shown that those with a bachelor's degree or higher have better health outcome measurements.⁶³ Among the older adults in Cleveland, just 11 percent have attained an education level of bachelor's degree or higher. This means 89 percent of older adults have not reached a level of education associated with more positive health outcomes which include lower rates of chronic illness and increased life expectancy. In addition to having less experience with higher education, older adults in Cleveland are largely unconnected to the local educational system. Only 13 percent of older adults were aware of local schools that included older adults in events and activities. Lack of connection to educational systems reduces participation in lifelong and intergenerational learning initiatives.



Data Source: U.S. Census Bureau, American Community Survey 2016 5-year Estimates

Community and Social Context

The most common type of social activity for older adults in Cleveland are family gatherings and 71.8 percent of older adults report participating in these on a regular basis. Fifty-two percent of older adults do not feel connected to their community and approximately 40 percent of older adults rarely or never participate in social or community events. Lack of social connection may result from not feeling welcome at events and activities. More people are interested in participating in events such as physical recreation activities, concerts, live theater and lifetime learning opportunities. These specific activities had fewer people who actually participated in them than those who expressed interest on the Age Friendly Assessment survey. This indicates either a lack of opportunity to participate or lack of awareness of these programs. Any of these social opportunities would increase social integration. Sixty-four percent of older adults surveyed for the Age Friendly assessment reported they do not, or are not sure, if they have access to fitness activities geared toward them. This would include Silver Sneakers as well as city recreation center senior classes. In addition to providing a health benefit, these types of

⁶³ Kaplan, R. M., Fang, Z. Kirby, J. (2017) Educational attainment and health outcomes: data from the medical expenditures panel survey. *Health Psychology, 36,* 598-608.

classes also provide opportunities to increase social connectedness. While adult programming is open to anyone aged 18 and older, less than half of the city's 20 recreation centers offer programming specifically for older adults.

Discrimination within a community can reduce connection to that community and lead to social isolation. Fifty-nine percent of older adults in Cleveland agreed with the statement *"there are negative stereotypes about older adults."* Just 46 percent of respondents to the Age-Friendly Cleveland assessment survey agreed that older people are valued in the community.

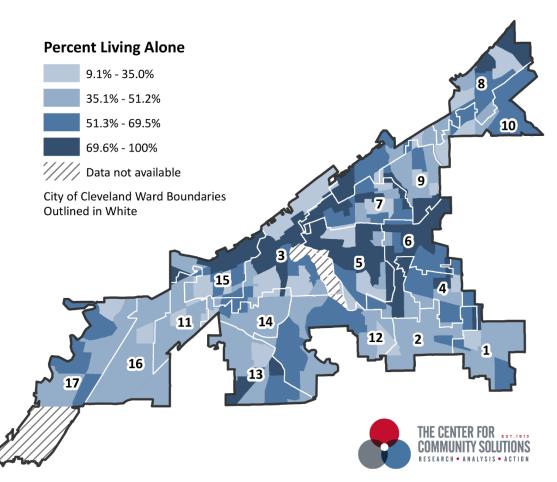
Cleveland has a long history of residential racial segregation and remains one of the most racially segregated cities in the country.⁶⁴ As multiple studies have demonstrated, residential racial segregation leads to health disparities and poorer outcomes for communities of color.⁶⁵ People of color make up more than 70 percent of the population in five wards in Cleveland; 1, 2, 4, 9, and 10. The combined older adult population of these wards is around 17,600 people. This group of nonwhite older adult residents who live in highly racially homogenous communities are at increased risk for poorer health behaviors and outcomes. Racial distribution maps in Cleveland overlaid onto health outcome maps, a clear pattern of high African-American populations and poor health outcomes emerge.⁶⁶

Living alone is a social determinant of health that can lead to social isolation, self-neglect and financial exploitation. In 2016, the U.S. Census estimates 20,300 adults aged 65 and older in Cleveland lived alone. Some parts of the city have higher rates of adults living alone than others. The map of wards detailed the percentage of older adults who lived alone in various wards in 2013, but it is likely the distribution has not changed dramatically over the past five years.

⁶⁴ Divided By Design Timeline: A historical tour of greater Cleveland's Segregation. <u>http://www.ideastream.org/programs/divided-by-design/timeline</u>

⁶⁵ William, D.R., Collins, C. (2001) Racial Residential Segregation: A fundamental cause of racial disparities in health *Public Health Reports*, 116 p. 404-416.

⁶⁶ 500 Cities Project: Local Data for Better Health <u>https://nccd.cdc.gov/500 Cities</u>



Percent of Cleveland Households with an Older Adult (Age 65+) Where the Older Adult is Living Alone

Source: U.S. Census Bureau, American Community Survey, 2013-2017 5-Year Estimates by Census Tract

Food

Lack of access to proper nutrition over the course of a lifetime plays a role in the health outcomes of older adults.⁶⁷ Lack of fresh fruit and vegetables paired with a diet that includes a lot of processed foods can result in chronic diseases that include diabetes, high blood pressure, cardiovascular disease, poor bone health and obesity among other diet-linked chronic conditions. While these diseases often appear in a later stage of life, changing a diet can slow down the progression of the disease and delay disabilities related to disease.⁶⁸ The Age-Friendly Cleveland Assessment found that while food insecurity is an issue among older adults who live in the city, many are able to find the food they need through food assistance programs like congregate meals, food pantries and home-delivered meals. Even with a

⁶⁷ Anthes, Loren. "Hungry for Policy: Searching for Solutions to Food Insecurity in Ohio Medicaid" The Center for Community Solutions, 23, April 2018, <u>https://www.communitysolutions.com/research/hungry-policy-searching-solutions-food-insecurity-ohio-medicaid/</u>

⁶⁸ WHO Technical Report Series 916, Diet Nutrition and The Prevention of Chronic Diseases, 2003

well-developed network of food support within the city, 25 percent of older adults do not or are not sure if they have access to healthy affordable food within their own neighborhood. This translates to just more than 18,000 older adults in Cleveland.

Health Care System

Cleveland is fortunate to have a wealth of health care providers through the three major hospital systems, University Hospitals, Metro Health and the Cleveland Clinic, as well as several federally qualified health clinics within its borders. Unsurprisingly, older adults in Cleveland report a high level of access to the type of care provided at hospitals and health clinics. More than 99 percent of residents in Cleveland aged 65 and older have health insurance and 87 percent of those between the ages of 55 to 64 have health insurance.⁶⁹ Just 2 percent of older adults who responded to the Age Friendly Cleveland survey reported they were unable to get medical appointments when needed and 10 percent could only sometimes get appointments. Seventy-five percent reported convenient access to emergency rooms or urgent care facilities.

In-home supports and long-term care appear to be less accessible to older adults who live in Cleveland. Forty percent of older adults are unsure about access to medical equipment, not knowing where or how to get equipment that can help maintain independence. Sixty-seven percent of older adults who responded to the Age Friendly survey do not have access to, or are unsure about home health providers and 64 percent were unsure or did not have access to home care services such as personal care and housekeeping. Lack of access to these types of services can lead to stays at skilled nursing facilities. Fiftysix percent of older adults reported they were unsure if they could find a care facility or nursing home to meet their needs if they should need a higher level of care than can be provided within their home. Providing linguistic and cultural competency in health care providers is particularly important for residents with limited English proficiency and members of minority groups. At this time, it does not appear data exists to gauge at what level older adults living in Cleveland feel as if they have access to health care providers who meet their cultural and linguistic needs.

Based on survey data from older adults living in Cleveland, one can calculate an estimate for how many of those older adults are impacted by specific social determinants of health. Adverse experiences related to these social determinants can lead to poor health outcomes, which increases the likelihood more long-term services and supports are needed. We can assume a higher percentage of older adults who live in Cleveland will need access to these services compared to their peers living in communities that do not experience social determinants of health negatively.

⁶⁹ US Census American Community Survey 2016 Five Year Estimates

Social Determinants with Negative Impact on Health Outcomes	Estimate of the Number of Older Adults in Cleveland Impacted	Percent of 60+ Population
Economic Stability	22,245	30%
Transportation	16,800	23%
Food Insecurity	18,000	25%
Safety from Crime	16,800	23%
Walkability	43,898	60%
Housing Affordability	11,706	16%
Utility Affordability	13,169	18%
Home Maintenance	36,582	50%
Home Modifications	49,751	68%
Educational Attainment	65,115	89%
Valued in Community	39,508	54%
Community Connection	38,045	52%
Residential Segregation	16,787	23%
Living Alone	20,368	28%
Medical Bills	32,923	45%
Afford Prescriptions	25,607	35%
Medical Care Access	1,463	2%
Home Health Care Access	49,019	67%

Appendix III: Cost analysis of long-term care in Cleveland

Medicaid

Over the past 15 years, Medicaid has shifted from primarily funding long-term care in long-term care facilities to funding waivers that provide long-term care in home and community-based settings. The Ohio Department of Medicaid has aligned with the federal priority of balancing the number of older adults and adults with disabilities who receive care in the community and those who receive care in long-term facilities. This was achieved through the Federal Balancing Incentive Program⁷⁰ which was implemented to increase the percentage of community-based services, and decrease the percentage of facility-based services, Medicaid long-term care services and supports. In 2013, 42.7 percent of Medicaid long-term care funds were spent on community and home-based supports, and by June 2015, 56.8 percent of funds were spent on community supports.⁷¹ As a result, the number of older adults who receive home and community-based services has increased in recent years, as they have been able to access Medicaid through a waiver program known as PASSPORT. PASSPORT waives the requirements to receive a skilled nursing level of care in a facility.

To qualify for long-term care through Medicaid, whether through a home and community-based waiver or through a long-term care facility, the individual must meet income and asset-eligibility requirements. The income level for long-term care eligibility is referred to as the Special Income Level (SIL) and is set at 225 percent of the Federal Poverty Level. For 2018, this amount is \$2276 monthly or \$27,312 annually. A Qualified Income Trust, also known as a Miller Trust, allows individuals over the Medicaid Special Income Level to become financially eligible for long-term care services through Medicaid. The individual whose income is more than 225 percent of the federal poverty level is placed in the trust, with the State of Ohio named as the sole beneficiary.

For an individual who receives care in a long-term care facility and is enrolled in Medicaid, the first \$2,276 of the individual's monthly income goes to the long-term care facility. The remainder of the monthly income is placed in the Miller Trust. Individuals are able to access \$30 from the trust for a personal allowance. Money from the trust is then used to reimburse the long-term care facility for the expense of caring for the individual. If money remains in the trust following the individual's passing, the remaining funds become assets of the state.

For an individual who receives long-term care through a home and community-based Medicaid waiver, such as PASSPORT, the individual keeps the first \$2,276 of monthly income. This allows the individual to continue to cover the costs of housing and basic needs. Any income in excess of \$2,276 is placed into a Miller Trust and used to reimburse the agency administering the PASSPORT waiver for the individual's care. If money remains in the trust following the individual's passing, the remaining funds become assets of the state.

In both instances of using Medicaid for long-term care, if the individual's cost of care was more than the amount in the Miller Trust, the state can recover costs through estate recovery. Many individuals are wary of estate recovery and opt to privately pay as long as possible to avoid risking a loss of transfer of wealth that occurs within families upon the passing of a homeowner. Asset limits of \$2,000 per individual also prevent some who would otherwise be income eligible for waiver programs from accessing this benefit.

⁷⁰ https://www.medicaid.gov/medicaid/ltss/balancing/incentive/index.html

⁷¹ Balancing Incentive Program Ohio Dashboard, August 19, 2015

Private pay

Individuals who need long-term care may use private funds to pay for care, either in a facility or in a home and community-based setting. Upon needing care, an individual's options for funds include using personal income, savings, investments and contributions from outside sources such as family members or charitable organizations. The need, level of care and access to an unpaid caregiver will often determine the length of time an individual is able to privately pay for their care.

Long-term care insurance

A third way to pay for long-term care is through long-term care insurance. Policies for this type of insurance are sold in the private market, and can vary greatly in cost and coverage. Policies may cover some or all of nursing home care, home health care, respite care, hospice care, personal care in the home, assisted living facility services and adult daycare center services. Premiums are based on age, the older an individual is when the policy is purchased the higher the premiums. Policies typically have an elimination or deductible period in which the individual pays out of pocket for a set number of days. The benefit period can vary as well, the longer the period (up to lifetime) the greater the monthly cost. While this may be an option for those who can afford the premiums, a small percent of Ohioans currently have long-term care insurance policies and within a year of first accessing the policy benefits, most have reached the coverage limits of their policy.

The level of service provided will vary greatly on the individual's need. The following model was developed to gauge the costs at various need levels and methods of paying for care. The model was originally developed for the 2018 Summit County Older Adults Needs Assessment and Long-Term Care Cost Analysis and has been adapted for Cleveland. This model relies on three indices, the Elder Index, the Genworth Cost of Care Study and the federal poverty level, to generate the amount of funds an individual will have remaining once basic needs and long-term supports are paid.

The Elder Index⁷² was developed in partnership with the Women's Policy Research, National Council on Aging and the University of Massachusetts Boston. The index provides a basic needs budget localized to Cuyahoga County, the smallest geography available. The index provides separate budgets for households made up of single people and couples, as well as three housing possibilities; with mortgage, without mortgage and renting. The budget includes housing (utilities included), food, transportation, healthcare and miscellaneous expenses.

Single elderly adult age 65+ monthly budget	Total Expense	Housing	Food	Trans- portation	Health Care	Misc.
Without Mortgage	\$1,679	\$508	\$256	\$234	\$401	\$280
Renter	\$1,792	\$621	\$256	\$234	\$401	\$280
With Mortgage	\$2,347	\$1,176	\$256	\$234	\$401	\$280

Elderly couple age 65+ monthly budget	Total Expense	Housing	Food	Trans- portation	Health Care	Misc.
Without Mortgage	\$2,570	\$508	\$470	\$362	\$802	\$428
Renter	\$2,683	\$621	\$470	\$362	\$802	\$428
With Mortgage	\$3,238	\$1,176	\$470	\$362	\$802	\$428

⁷² www.basiceoncomicsecurity.org

Home and community-based care

From the Genworth study daily rates, various home-based care scenarios and associated costs were developed. These represent possible combinations of paid care an individual and family may arrange to receive while living in a community-based setting.

Care Option	Service Combination	Monthly Cost
Adult day & homemaker combination	2 days homemaker, 4 days homemaker health aide, 3 days adult day health care	\$3,972
Adult daycare on weekdays & homemaker health aide on weekends	5 days adult day health care, 2 days homemaker health aide	\$2,244
Homemaker services as primary caregiver	7 days homemaker health aide, 3 days homemaker	\$5,484
Homemaker health aide on weekdays & weekend family caregiver	5 days homemaker health aide	\$2,760

The 2018 incomes for 200, 400 and 600 percent of the federal poverty level were chosen to represent those who qualify for Medicaid waivers (200 percent), those who can potentially afford to privately pay (600 percent) and those who neither qualify for Medicaid waivers nor can afford to privately pay (400 percent).

The Cuyahoga County Department of Senior and Adult Services offers programs that are similar in service to PASSPORT but are available to those who are not eligible for Medicaid programs. To be eligible for these programs, an older adult must be "managing expenses on a modest monthly income with limited financial resources." The Options for Independent Living program is funded by the Cuyahoga County Health and Human Services Levy. The program has a weekly standard of care that includes five home-delivered meals, one emergency response button, three hours of homemaking, two hours of personal care and four one-way trips for medical transportation. Using Genworth estimates, the homemaker and personal care hours through Options would be roughly equivalent to \$108 a week.

This model is based on income alone and does not consider assets or long-term care insurance in covering the cost of care.

Single eld \$1,679									
Incon	ne Level	Benefit Program		Adult Day & Homemaker Combination \$3,972	Adult Daycare on Weekdays & Homemaker Health Aide on Weekends \$2,244	Homemaker Services as Primary Caregiver \$5,484	Homemaker Health Aide on Weekdays & Weekend Family Caregiver \$2,760		
Percent FPL	Monthly Income	PASSPORT Waiver	DSAS OPTIONS	Income rema	aining after basi	c expenses and	care needs are met		
200%	\$2,023.00	Up to \$14,700	\$0.00	\$344.00	\$344.00	\$344.00	\$344.00		
400%	\$4,047.00	\$0.00	\$108.00	(\$1,712.00)	\$16.00	(\$3,224.00)	(\$500.00)		
600%	\$6,072.00	\$0.00	\$0.00	\$421.00	\$2,149.00	(\$1,091.00)	\$1,633.00		

Elderly c \$2,570								
Incon	ne Level	Benefit Program		Adult Day & Homemaker Combination \$3,972	Adult Daycare on Weekdays Homemaker & Health Aide on Weekends \$2,244	Homemaker Services as Primary Caregiver \$5,484	Homemaker Health Aide on Weekdays & Weekend Family Caregiver \$2,760	
Percent FPL	Monthly Income	PASSPORT Waiver	DSAS OPTIONS	Income remair	ning after basic	expenses and c	are needs are met	
200%	\$2,743.00	Up to \$14,700	\$0.00	\$173.00 \$173.00 \$173.00 \$173.0			\$173.00	
400%	\$5,487.00	\$0.00	\$108.00	(\$947.00)	\$781.00	(\$2,459.00)	\$265.00	
600%	\$8,232.00	\$0.00	\$0.00	\$1,690.00	\$3,418.00	\$178.00	\$2,902.00	

_	Single elderly adult (65+) Renter: Monthly Expenses \$1,792							
Incom	ne Level	Benefit Pro	gram	Adult DayAdult Daycare on Weekdays Homemaker \$3,972Homemaker 			Health Aide on Weekdays & Weekend Family Caregiver	
Percent FPL	Monthly Income	PASSPORT Waiver	DSAS	Income remair	ning after basic ex	openses and car	re needs are met	
200%	\$2,743	Up to \$14,700	\$0	\$951.00 \$951.00 \$951.00 \$951.0			\$951.00	
400%	\$5,487	\$0	\$108	(\$169.00)	\$1,343.00	(\$1,681.00)	\$1,043.00	
600%	\$8,232	\$0	\$0	\$2,468.00	\$4,196.00	(\$851.00)	\$1,713.00	

	Elderly couple (65+) Renter: Monthly Expenses \$2,683							
Incon	ne Level	Benefit Pro	gram	Adult Day & Homemaker Combination \$3,972	Adult Daycare on Weekdays Homemaker & Health Aide on Weekends \$2,244	Homemaker Services as Primary Caregiver \$5,484	Homemaker Health Aide on Weekdays & Weekend Family Caregiver \$2,760	
Percent FPL	Monthly Income	PASSPORT Waiver	DSAS	Income remair	ning after basic ex	openses and car	e needs are met	
200%	\$2,743	Up to \$14,700	\$0	\$60.00 \$60.00 \$60.00				
400%	\$5,487	\$0	\$108	(\$1,060.00)	\$452.00	(\$2,572.00)	\$152.00	
600%	\$8,232	\$0	\$0	\$2,789.00	\$2,789.00	\$65.00	\$2,789.00	

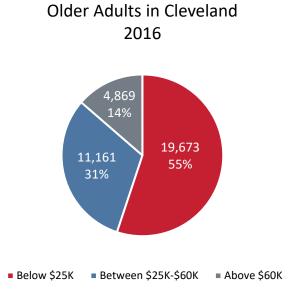
Single elderly adult (65+) with a Mortgage: Monthly Expenses \$2,347								
Incon	ne Level	Benefit Pro	gram	Adult Day & On Weekdays S Homemaker Homemaker & P Combination Health Aide on C \$3 972 Weekends		Homemaker Services as Primary Caregiver \$5,484	Homemaker Health Aide on Weekdays & Weekend Family Caregiver \$2,760	
Percent FPL	Monthly Income	PASSPORT Waiver	DSAS	Income remaining after basic expenses and care needs are met				
200%	\$2,023	Up to \$14,700	\$0	(\$324.00) (\$324.00) (\$324.00)				
400%	\$4,047	\$0	\$108	(\$2,164.00) (\$772.00) (\$3,676.00) (\$1,288.00)				
600%	\$6,072	\$0	\$0	(\$247.00)	\$1,481.00	(\$1,759.00)	\$965.00	

Elderly co \$3,238	Elderly couple (65+) with a Mortgage: Monthly Expenses \$3,238							
Incon	ne Level	Benefit Pro	ogram	Adult Day & Homemaker Combination \$3,972	Adult Daycare on Weekdays Homemaker & Health Aide on Weekends \$2,244	Homemaker Services as Primary Caregiver \$5,484	Homemaker Health Aide on Weekdays & Weekend Family Caregiver \$2,760	
Percent FPL	Monthly Income	PASSPORT Waiver	DSAS	Income remai	ning after basic e	xpenses and ca	re needs are met	
200%	\$2,743	Up to \$14,700	\$0	(\$495.00)	(\$495.00)	(\$495.00)	(\$495.00)	
400%	\$5,487	\$0	\$108	(\$1,615.00) \$113.00 (\$3,127.00) (\$403.00			(\$403.00)	
600%	\$8,232	\$0	\$0	\$1,362.00	\$3,002.00	(\$82.00)	\$2,482.00	
Break eve	en income			\$5 <i>,</i> 987	\$4,347	\$8,314	\$4,867	

As the model demonstrates, there are situations when the level of care and type of service cannot be covered by the individual's income alone. The group that experiences the most financial struggle is the group who doesn't financially qualify for Medicaid but is below an income that could support privately paying for services. Single older adults within the income range of \$27,310 and \$48,564 and couples with joint incomes between \$37,030 and \$65,844 will likely struggle to afford a safe level of care for an individual who needs a skilled level of care, and wishes to remain in a home and community-based setting. The monthly break-even income, the amount need to fully cover basic and care needs, is listed below for housing and care scenario.

Break even income	Adult Day & Homemaker Combination	Adult Daycare on Weekdays Homemaker & Health Aide on Weekends	Homemaker Services as Primary Caregiver	Homemaker Health Aide on Weekdays & Weekend Family Caregiver	
Single elderly adult 65+					
Without a mortgage	\$5,651	\$3,923	\$7,163	\$4,439	
Renter	\$5,764	\$4,036	\$7,276	\$4,552	
With a mortgage	\$6,319	\$4,591	\$7,831	\$5,107	
Elderly couple 65+					
Without a mortgage	\$6,542	\$4,814	\$8,054	\$5,330	
Renter	\$6 <i>,</i> 655	\$4,927	\$8,167	\$5 <i>,</i> 443	
With a mortgage	\$7,210	\$5,482	\$8,722	\$5,998	

In Cleveland there are approximately 11,161 senior households with incomes in the 'at-risk' zone of between \$25,000 and \$60,000, representing more than 30 percent of the older adult population. The financial and emotional weight of needing skilled care goes beyond the individual, and impacts familial



and nonprofessional caregivers. Family members and other loved ones often cover the gap between what the individual needs and what the individual can afford. This comes both in the form of the physical act of caregiving, and contributing financially to the cost of care.



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