

Healthy aging across the lifespan:

Emerging approaches to understanding and meeting the needs of aging individuals

August, 2024







Executive summary

Since 2012, UnitedHealthcare Community & State has convened the National Advisory Board (the Board) to provide recommendations and innovative approaches to improve how UnitedHealthcare is able to best serve members with special health care needs. Board members include national experts and leading champions from aging and disability advocacy backgrounds, plan members, and family members of individuals with special health care needs. In 2024, the Board discussed the need to challenge the conventions related to aging, stressing that individuals' experiences while aging are influenced by their diverse intersectional identities and the contexts in which they live.

To better understand the landscape of research, policies, and programs supporting individuals ages 50 to 70, UnitedHealthcare worked with Healthsperien to develop this series of papers. The first paper explores the current landscape, using a strengthsbased approach and life course perspective, to understand the various experiences of those within this age range across health care, functional, economic, and health-related social needs. The challenges and strengths of this population are illustrated through four fictional personas and their experiences across each domain. The subsequent paper explores how policies impact this age group, and offer recommendations for plans, states, and federal policymakers to ensure that they are adequately serving the needs of individuals earlier in the aging process and are not perpetuating ageist policies and systems.

Health care utilization

Research on health care utilization among this age group is limited, despite early health risks and prevention significantly influencing long-term aging outcomes. Data indicate that older Americans face higher chronic conditions and disability risks, often delaying necessary care due to costs and lack of insurance. Medicaid expansion under the Affordable Care Act (ACA) has improved access for midlife adults, but disparities remain, especially for people of color, low-income individuals, and those in non-expansion states. Preventive services and regular check-ups are crucial, yet access heavily depends on affordable health insurance, highlighting the need for expanded coverage and additional research to address the needs of this population.

Functional needs

Studies show a growing prevalence of cognitive and functional impairments among adults in this age group, with the current care systems struggling to adequately address these issues. Traumatic brain injuries (TBI) and acquired brain injuries (ABI) pose additional challenges, particularly affecting older veterans and underserved populations, highlighting the need for specialized rehabilitation services. Although large cohort studies offer valuable data on stress and cognitive decline, inconsistent measurement tools complicate research. Positive factors like education, healthy lifestyles, and social engagement help to maintain cognitive health, but economic and psychological stressors contribute to declining health status among this age group.



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Health-related social needs

To better categorize and understand the how aging impacts this population in the U.S., it is important to consider not only the rising number of older adults and income inequality but also health-related social needs such as housing, nutrition, transportation, and social connection. Research shows that generally older adults have less access to affordable and accessible housing, nutrient dense food, affordable and accessible transportation, and are less likely to have adequate social connection when compared to their younger counterparts. Disparities related to race, ethnicity, gender, and sexual orientation exacerbate the healthrelated social needs of older adults.

Economic needs

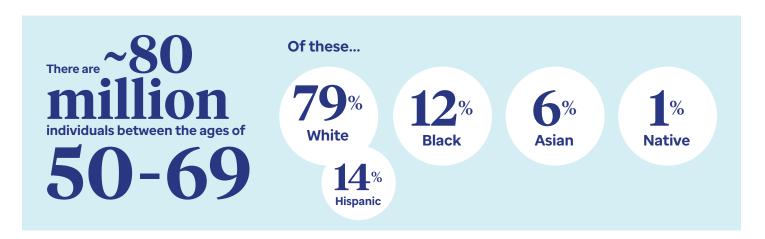
Adults often face significant economic challenges as they age, particularly regarding retirement savings and health care costs. Many individuals ages 50 to 64 face high out-of-pocket medical expenses and reduced access to employer-sponsored coverage, with a considerable portion lacking any retirement savings. With long-term care costs expected to rise substantially, ensuring financial security and adequate health care for this demographic is increasingly crucial. Insufficient retirement savings, decreased access to employer-sponsored plans, and increased caregiving responsibilities further exacerbate financial strain on older adults.

Advancing new approaches to healthy aging

There is relatively little research or resources tailored for this population, contributing to the American systems failure to adequately support older adults. If those in the earlier stages of aging were given the supports necessary for them to maximize their health, welfare, and independence, the U.S. may rely less on intensive eldercare options as people reach their eighties and nineties. 2



Population demographics



According to the 2023 U.S. Census estimates, there are approximately 80 million individuals between the ages of 50 to 69 in the U.S.¹ Of those, 79% of the population identify as white, 12% are Black, 6% are Asian, and 1% are American Indian or Alaskan Native. Additionally, 14% have Hispanic ethnicity.² The majority (64%) are married, and native U.S. citizens (81%).³ About one-third of adults in this age range have a college or advanced degree, about the same number as those with only a high school degree.⁴ For a full list of these and other demographic characteristics, please see Table 1 in the Appendix. This paper also examines trends and disparities unique to subpopulations within this age range, to challenge the conventional understanding of older adults being a homogenous population and highlight the need for additional knowledge and supports in anticipation of future generations of older adults.

Despite the diversity represented in this population, older adults are broadly defined by their deficits: leaving the workforce, increasing health care costs and burdens, and decreased capability. These negatively held views on aging contribute to widespread ageism in the U.S., creating stereotypes, prejudice, and discrimination directed towards people based on their perceived age.⁵ Additionally, these negative perceptions have significantly shaped how leaders think about, interact with, and develop solutions for older adults. These decisions led to health care, social service, and economic systems that far too often fail to consider aging individuals, are insufficient to meet their needs, or directly contribute to the discrimination and disparities they face.

Older adults from underrepresented communities experience numerous barriers and harms throughout their lifetime: challenges accessing care, disparities in care outcomes, unfair treatment and discrimination, and higher poverty rates.^{6,7} The consequences of discrimination compound as individuals age, contributing to higher rates of chronic diseases, disability, and lower preparedness to retire and age in place.^{8,910} For example, American Indian and Alaskan Native communities have significantly lower life expectancies and disproportionately high rates of poverty, food insecurity, and deaths due to chronic diseases.¹¹ Simultaneously, tribal communities have exhibited tremendous resilience in the face of these disparities, experiences of discrimination, and generational trauma. Tribal elders are respected community leaders, playing important parts of their communities cultural and spiritual practices.¹²

- ² Ibid.
- ³ Ibid. ⁴ Ibid.

- ⁶ Five Facts About Older Adults' Health Care Experiences by Race and Ethnicity
- ⁷ Precarious Aging: The Spatial Context of Racial and Ethnic Disparities in Economic Security
- ⁸ Five Facts About Older Adults' Health Care Experiences by Race and Ethnicity
- ⁹ Special Report Race, Ethnicity and Alzheimer's in America

¹¹ Ibid.

¹ Age and Sex Composition in the United States: 2023

⁵ COMMUNICATION BEST PRACTICES: Reframing Aging Initiative Guide to Telling a More Complete Story of Aging

¹⁰ Racial and ethnic variances in preparedness for aging in place among US adults ages 50-80

¹² Justice for Tribal Elders: Issues Impacting American Indian and Alaska Native Older Adults

Data on the gender identities and sexual orientation of this age group vary significantly among different survey tools and populations. National surveys estimate that anywhere between 760,701 to 3.5 million adults ages 50 to 70 identify as LGBTQ+, and about 0.3% of adults in this group identify as transgender or non-binary, a small proportion of the overall LGBTQ+ population in the U.S.^{13,14} However, LGBTQ+ individuals in this age group have undergone significant social, cultural, health and economic shifts since they came of age in the 1960s and 70s.¹⁵ They occupy a unique position within the overall population; for example, they typically rely more heavily on partners or friends than family members for care and support, and report high rates of disability, mental illness, and discrimination.^{16,17}

Over recent decades, advances in community integration, deinstitutionalization, and long-term care and medical care have enabled more individuals with disabilities to reach older ages.¹⁸ For many diagnosed with a disability at the beginning of their lives, living to age 50 seemed unlikely, if not impossible. For these individuals, reaching older adulthood is a milestone achievement to be celebrated. However, emerging research suggests that the interaction of disabilities and age-related health changes contributes to secondary health conditions, earlier onset of aging-related changes, and longer-term disability-related complications.¹⁹ Similarly, as individuals with disabilities tend to have lower economic and social resources than those without disabilities, they are disproportionately likely to experience socioeconomic harms related to aging.

Most Americans over the age of thirty believe the signs of old age are the loss of independence and reduced functional ability: forgetting things (55%), trouble walking (55%), inability to drive (68%), and inability to live on their own (79%).²⁰ Health is the top priority of all age groups, but those in their 50s and 60s approaching older adulthood are the only group who rates independence as their second highest priority. Individuals with disabilities prioritize maximizing independence through the services they receive and their living arrangements.²¹ Across all populations, individuals' views on aging evolve as they age. About half of the adults over the age of 30 surveyed reported feeling optimistic and confident about aging.²² Another poll found that most people felt more comfortable being themselves as they have gotten older (88%) and their life is better than they thought it would be (65%).²³



- ¹³ LGBTQ+ DATA AVAILABILITY: WHAT WE CAN LEARN FROM FOUR MAJOR SURVEYS
- ¹⁴ About 5% of young adults in the U.S. say their gender is different from their sex assigned at birth
- ¹⁵ Historical and generational forces in the Iridescent Life Course of bisexual women, men, and gender diverse older adults
- ¹⁶ The Aging and Health Report: Disparities and Resilience among Lesbian, Gay, Bisexual, and Transgender Older Adults
- ¹⁷ The Future of LGBT+ Aging: A Blueprint for Action in Services, Policies, and Research
- ¹⁸ Quality-of-Life Outcomes of Older Adults with Severe Disabilities
- ¹⁹ Ageing, Diversity and Equality: Social Justice Perspectives, pg. 243
- ²⁰ PERCEPTIONS OF AGING DURING EACH DECADE OF LIFE AFTER 30
- ²¹ Organizations' Perspectives on Successful Aging with Long-Term Physical Disability

22 Ibid.

²³ Everyday Ageism and Health

Healthy aging across the lifespan

Despite these relatively positive self-reported views, older Americans are still likely to experience ageism. Only 20% of people age 30+ reported being excited to age.²⁴ Over a third of adults ages 50 to 80 included in a different survey agreed with at least one form of internalized ageism, such as that feeling lonely, depressed, sad, or worried are normal parts of getting older.²⁵ The vast majority (82%) of older adults reported regularly experiencing at

 $\begin{array}{c} Agism \text{ is reported to happen} \\ \text{ in over } 82^{\%} \text{ of older adults} \end{array}$

least one form of ageism in their lives, and these experiences were more commonly reported among individuals with chronic health conditions, worse self-rated physical and mental health, less education, and lower socioeconomic status.^{26,27} These negative experiences are compounded by a lifetime of stress, discrimination, poor health habits, economic instability, and other hardships. As a result, those in their 50s are experiencing higher rates of chronic diseases, mental distress, and socioeconomic instability as they enter the later stages of their lives.

Health care utilization

There is relatively little research on the health care utilization of individuals ages 50 to 70, despite the widely accepted theory that health risks and prevention earlier in individuals' lives influence their long-term aging outcomes. To understand the true impact of the lack of supports for this age group within the system and trends for the future as more individuals age into this population, additional research investments are needed. From the available data, older Americans clearly face higher rates of chronic conditions and disability risks and are significantly more likely to delay or forgo necessary care due to costs and lack of insurance. The U.S. National Health Interview Survey (2013-2018) found that adults ages 50 to 64 without health insurance were at least seven times more likely to postpone or skip needed health care compared to their insured peers.²⁸ Additionally, these uninsured individuals were only 15% to 23% as likely to have

had contact with a health care professional in the past year. Expanding health insurance coverage to this age group could substantially improve health care access, reduce morbidity and mortality, and enhance their overall quality of life.²⁹

Differentiated health care access and utilization dynamics characterize this population, who are dictated by their insurance coverage, whether through commercial insurance, Medicaid, Medicare, or those dually eligible for Medicare and Medicaid. A recent analysis on the 50+ population in Medicaid, considered midlife, from AARP discussed that adults ages 50 to 64 constitute 12% of the

Uninsured older adults are Seven times more likely to skip getting needed health care

Medicaid population.³⁰ This group is racially and ethnically diverse, though slightly less so than the overall Medicaid population. States that expanded Medicaid under the ACA have an average of 23% of midlife adults enrolled in Medicaid, compared to only 10% in non-expansion states. Nearly 75% of midlife adult Medicaid enrollees live in urban areas, with notable differences between expansion and non-expansion states. Additionally, nearly half of midlife Medicaid enrollees in non-expansion states are also enrolled in Medicare, often due to disabilities or chronic diseases, indicating that midlife enrollees in non-expansion states may be sicker and in need of more care than those in expansion states. For Medicaid and dually eligible beneficiaries, Medicaid's unique role in financing long term services and supports (LTSS) is essential to consider when thinking of ways to protect this population from falling through gaps in the system.

29 Ibid.

 $^{^{\}rm 24}\,$ PERCEPTIONS OF AGING DURING EACH DECADE OF LIFE AFTER 30 $\,$

²⁵ Everyday Ageism and Health

²⁶ Ibid.

²⁷ Differences and Disparities in Ageism Affecting Older US Adults: A Review

²⁸ Unmet Healthcare Needs and Healthcare Access Gaps Among Uninsured U.S. Adults Aged 50-64

³⁰ Medicaid in Midlife: A Profile of Enrollees Ages 50 to 64

Healthy aging across the lifespan

Trends around prevention as a means of protecting this population from the higher rates of chronic conditions and disability risks are at the forefront of the aging conversation around midlife and near-older adults.³¹ However, the ability to engage in preventive services, especially those that require seeing a provider, relies heavily on this population's access to affordable services – which often require health insurance.

This population, when asked about health care preferences, responded that their care preferences were usually or always considered seven out of ten times, with caveats for different populations including people of color, women, those with partners, and amidst income status.³² The trend improved for white people in this age grouping but declined for people of color, who were more likely to report having their care preferences never considered. Additionally, the trend declined for those in the Southern region, those who never married, and those with incomes lower than \$30,000 a year, indicating the disparities within the population itself once socioeconomic factors were considered.



Since its inception, Medicare has helped cover health care costs and safeguard the financial security of individuals ages 65 and older. However, adults ages 60 to 64, who are nearing Medicare eligibility, often face significant coverage gaps and higher health care costs. Approximately 58% of this group receive insurance through their employer, 11% purchase it through marketplaces or the individual market, 11% have Medicaid, and 10% qualify for Medicare due to disability or specific health conditions, while about 8% remain uninsured.³³ Although the ACA has improved coverage options for those not eligible for Medicare, many still encounter substantial cost sharing and lack coverage for essential services such as dental care.³⁴ The lack of research into the aging process for those ages 50 to 70, and the predominant focus on older adults ages 65 and older who are eligible for Medicare, leaves significant gaps in understanding the needs and experiences of the near-older adult population. Addressing these gaps is crucial to ensure adequate health care access, support, and preventive services for individuals in this age group, thereby improving their long-term aging outcomes and ensuring consistent health care utilization for this population.

³¹ What Do We Know About Healthy Aging?

³² For People 50+ Care Preferences Matter

³³ Older Adults on Medicare and Those Near Medicare Age Face Cost Barriers to Care

³⁴ Ibid.

Healthy aging across the lifespan

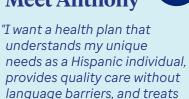
Health care utilization in practice: Anthony's experiences

Anthony is a Hispanic man in his 60s who has been diagnosed with chronic back pain, high blood pressure, and pre-diabetes. He recently lost his job as a commercial trucker after failing a required physical exam. After losing his job, Anthony is likely without stable health insurance, which prevents him from being able to see a provider regularly to manage his chronic conditions. High blood pressure and pre-diabetes, in particular, are exacerbated by Anthony's stress over being out of work.^{35,36} Without insurance, Anthony is more likely to delay or forgo necessary health care than his insured peers. If he is able to enroll in an individual marketplace plan, that could provide Anthony with the resources he needs to juggle these priorities: ensuring he has access to his care team to manage his chronic health conditions, providing information and referral assistance to other programs that help with financial, housing, and nutrition supports, and care management and navigation supports.



Meet Anthony

me with respect."



- Hispanic man, 60s
- Without stable insurance
- Limited access to care for chronic conditions
- Limited English proficiency (LEP)
- Experienced racism and stereotypes from providers
- Unemployed after failing a physical exam

Across the United States, there are about 26 million people who have Limited English Proficiency (LEP) and roughly 62% of the 26 million are Hispanic individuals.³⁷ In addition to Anthony's inability to access quality care due to a lack of insurance, he was likely already experiencing difficulties in receiving quality care while he was employed due to racism and language barriers between himself, his providers, and workers across the health care system. In 2019, only 5.8% of practicing physicians identified as Hispanic.³⁸ Compounding on the language barrier, Anthony has most likely experienced racism from providers when seeking care in the past, which significantly contributes to racial disparities in health. Providers often stereotype Hispanic patients as noncompliant and engaging in risky behaviors.³⁹

Without proper supports and interventions for Anthony's health and socioeconomic circumstances, his health care utilization will decrease or become non-existent as he transitions into this phase of his life and his overall health could become increasingly worse without proper care, making healthy aging more difficult for him.

³⁵ Stress and high blood pressure: What's the connection?

³⁶ What Is Prediabetes?

³⁸ Diversity in Medicine: Facts and Figures 2019

³⁷ Language Barriers in Health Care: Findings from the KFF Survey on Racism, Discrimination, and Health

³⁹ Use of Race in Clinical Diagnosis and Decision Making: Overview and Implications

Functional needs

Among adults ages 45 to 64, there is a growing prevalence of cognitive and functional impairments, which are inadequately addressed by our current systems of care.⁴⁰ Currently, approximately 16% of individuals in this age group report having a functional impairment, a 3% increase over the past decade.⁴¹ Nearly 15% of adults ages 55 to 64 years have difficulty performing at least one activity of daily living (ADL).⁴² The prevalence of subjective cognitive decline (SCD) is 10.8% among adults 45 to 64 years old.⁴³ This trend reflects a broader decline in health within this demographic, influenced by exposure to stress, chronic conditions, lifestyle choices, and socioeconomic factors.^{44, 45, 46, 47} If these patterns continue unchecked, the prevalence of functional impairments is expected to rise further.⁴⁸

TBI and ABI also pose significant challenges for healthy aging in older adults, who have the highest rates of TBIrelated hospitalization and death compared to other age groups.⁴⁹ Importantly, older age negatively influences outcomes after TBI and ABI, with increased disability, reduced functional independence, and less community participation observed.⁵⁰ Older veterans with a history of TBI demonstrate worse functioning across multiple domains compared to peers without prior TBI, even when living independently.⁵¹ The high prevalence of TBI and ABI among individuals experiencing homelessness and housing insecurity is also concerning, as it is associated with poorer overall health and functioning in this population.⁵² Collectively, these findings highlight the need for tailored rehabilitation services, especially in the chronic period after injury for older adults with TBI to promote healthy aging.⁵³

Unmet health related social needs and disparities across the social drivers of health also disproportionately impact individuals with disabilities and functional needs. Those with disabilities are much more likely have very low or low food security than individuals without disabilities (32% vs. 9%), be worried about paying housing costs (46% vs. 24%), and to have delayed needed medical care because they didn't have access to transportation (10% vs. 1%).⁵⁴ Individuals who live in neighborhoods with greater disadvantages across education, employment, income, poverty, and housing – as assessed by the Area Deprivation Index (ADI) – had higher risk of cognitive decline and developing Alzheimer's disease or other related dementias.⁵⁵ Another study found that adults ages 65 and older with a greater number of social drivers of health risk factors had more functional needs and worse self-reported health than peers with fewer risk factors.⁵⁶ Targeted interventions are needed for this population to address these issues, as intact cognitive and functional abilities are vital for promoting healthy aging and maintaining independence and quality of life.⁵⁷

Cognitive and functional health can be maintained with these healthy lifestyle choices:



Effective stress management

Regular physical activity

Nutritious diets

⁴⁰ Historical Change in Midlife Health, Well-Being, and Despair: Cross-Cultural and Socioeconomic Comparisons

- ⁴¹ Functional Impairment in Middle-Aged Adults
- ⁴² Association of Functional Impairment in Middle Age with Hospitalization, Nursing Home Admission, and Death
- ⁴³ Subjective Cognitive Decline A Public Health Issue
- ⁴⁴ Functional Impairment in Middle-Aged Adults

⁴⁵ A life course approach to understanding stress exposures and cognitive function among middle-aged and older adults

- ⁴⁶ HRS Aging in the 21st Century
- ⁴⁷ Functional Impairment in Middle-Aged Adults

- ⁵⁰ Aging with Traumatic Brain Injury: Deleterious Effects of Injury Chronicity Are Most Pronounced in Later Life
- ⁵¹ Neurobehavioral Characteristics of Older Veterans with Remote Traumatic Brain Injury
- ⁵² Traumatic brain injury in homeless and marginally housed individuals: a systematic review and meta-analysis
- 53 Aging with Traumatic Brain Injury: Deleterious Effects of Injury Chronicity Are Most Pronounced in Later Life
- ⁵⁴ Disability-Based Disparities in Social Determinants of Health Among Working-Age Adults
- ⁵⁵ Association of Neighborhood Socioeconomic Disadvantage and Cognitive Impairment
- ⁵⁶ Black-White Disparities in Social and Behavioral Determinants of Health Index and Their Associations with Self-rated Health and Functional Limitations in Older Adults
- ⁵⁷ Functional impairment and decline in middle age: a cohort study

⁴⁸ Ibid.

⁴⁹ Traumatic Brain Injury in Older Adults: Epidemiology, Outcomes, and Future Implications

Healthy aging across the lifespan

Cognitive and functional impairments are typically assessed using various scales and tests, such as ADL and instrumental activities of daily living (IADL) performance evaluations and cognitive function assessments.⁵⁸ Large cohort studies, like the Midlife Development in the United States (MIDUS) Study and the University of Michigan Health and Retirement Study (HRS) offer valuable data on the relationship between stress exposure and cognitive decline.^{59,60} However, the lack of standardized measurement tools across studies poses a challenge for comparing results and synthesizing findings.⁶¹ Improving research efforts could involve developing more precise prognostic tools to identify high-risk individuals and expanding longitudinal studies to better capture long-term trends and intervention impacts.

Several factors contribute positively to cognitive and functional health among older adults. Higher education correlates with better cognitive function and lower risk for dementia and Alzheimer's disease.⁶² Healthy lifestyle choices, such as regular physical activity, nutritious diets, and effective stress management, are also significant in maintaining cognitive and functional health.^{63, 64, 65} Social engagement and strong support networks provide cognitive stimulation and help protect against cognitive decline.⁶⁶ Interventions aimed at improving physical health, such as controlling high blood pressure and encouraging exercise, offer long-term benefits for both cognitive and functional health.⁶⁷ Despite some protective factors such as higher educational attainment and reduced smoking rates, negative influences like economic stress and psychological distress continue to drive the decline in health status among older adults.⁶⁸



Addressing cognitive and functional impairments in older adults presents several challenges. These impairments are often dynamic, with individuals frequently moving between states of impairment and independence.⁶⁹ Long follow-up periods are necessary to evaluate the success of interventions, complicating efforts to measure effectiveness.⁷⁰ Additionally, there is a notable gap in evidence-based interventions specifically tailored for older adults.⁷¹ The variability in how functional impairments and cognitive outcomes are measured across different studies further complicates the development of standardized intervention strategies and hinders comparability.⁷²

- ⁵⁸ Assessment tools to evaluate Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL) in older adults: A systematic review ⁵⁹ Midlife in the United States: A National Longitudinal Study of Health & Well-Being
- ⁶⁰ The Health and Retirement Study
- ⁶¹ Functional social support and cognitive function in middle- and older-aged adults: a systematic review of cross-sectional and cohort studies
- ⁶² HRS Aging in the 21st Century
- ⁶³ A life course approach to understanding stress exposures and cognitive function among older and older adults
- ⁶⁴ Cognitive Health and Older Adults
- ⁶⁵ Promoting Functional Health in Midlife and Old Age: Long-Term Protective Effects of Control Beliefs, Social Support, and Physical Exercise
- ⁶⁶ Functional social support and cognitive function in middle- and older-aged adults: a systematic review of cross-sectional and cohort studies ⁶⁷ Cognitive Health and Older Adults
- 68 Moving prevention of functional impairment upstream: is middle age an ideal time for intervention?
- 69 Moving prevention of functional impairment upstream: is middle age an ideal time for intervention?

70 Ibid.

⁷¹ Association of Functional Impairment in Middle Age With Hospitalization, Nursing Home Admission, and Death

⁷² Functional social support and cognitive function in middle- and older-aged adults: a systematic review of cross-sectional and cohort studies

Healthy aging across the lifespan

Functional health in practice: Jane's experiences

Jane is a white LGBTQ+ woman in her 50s who lives with muscular dystrophy. She is dually eligible for Medicare and Medicaid and receives LTSS to manage her condition. Like nearly 15% of adults ages 55 to 64, Jane has trouble with at least one ADL, relying on LTSS for support.⁷³ Jane lives independently with her partner, who is also one of her caregivers. While her muscular dystrophy causes significant physical challenges, Jane's partner and other caregivers help her with daily tasks in order for her to go to work and live in the community. Research shows that 70% of adults ages 65 and older will develop severe LTSS needs before they die, and many rely on family and unpaid caregivers, like Jane's partner.⁷⁴ Families often provide most of the care and financial support for individuals with muscular dystrophy.75

Jane describes her experience of aging with muscular dystrophy as "slowing down early." Her physical body has deteriorated faster than those of her peers, increasing her physical limitations and reliance on her



Meet Jane



"I'm looking for a plan that really gets me as a LGBTQ+ woman living with muscular dystrophy. Inclusive care and financial assistance are important to me."

- White LGBTQ+ woman, 50s
- · Lives with muscular dystrophy
- Dually eligible for Medicare and Medicaid
- Lives independently with her partner, who is also her caregiver
- LGBTQ+ people often face obstacles as they age due to discrimination, and social stigma

caregivers.⁷⁶ As Jane's needs increase, accessible housing and transportation become increasingly critical. Although Jane currently lives independently, she and her partner worry about a future in which she may need round-the-clock care, which could cause financial strain on her and her partner if not paid for by Medicaid. Older adults with health problems tend to have less wealth than healthier older adults, and wealth typically declines when people develop health problems. Paid care is expensive, and while Medicaid may cover some LTSS costs for individuals who meet financial and functional criteria, access to those services is limited. As Jane's muscular dystrophy progresses and her needs increase, she may face barriers to accessing LTSS.⁷⁷

LGBTQ+ people often face obstacles as they age that impact their health and wellbeing due to a history of discrimination, social stigma, and isolation. This includes a lack of cultural competency training and minimal focus on the needs of LGBTQ+ older adults in medical training.⁷⁸ There is growing evidence of health disparities among LGBTQ+ older adults, making this population at-risk as defined by the Centers for Disease Control and Prevention (CDC).⁷⁹ Studies have found that LGBTQ+ older adults have higher rates of poor mental health, smoking, and limitations in ADLs compared to their heterosexual peers and engage in higher rates of risky behaviors, including excessive drinking. For Jane, these considerations are compounded by her intersectional gender identity and disability. Studies show that LGBTQ+ older adults are often forced to choose lower-quality LTSS due to a lack of inclusivity in the long-term care system.

- ⁷³ Association of Functional Impairment in Middle Age With Hospitalization, Nursing Home Admission, and Death
- ⁷⁴ What Is the Lifetime Risk of Needing and Receiving Long-Term Services and Supports?.
- ⁷⁵ Social difficulties and care burden of adult Duchenne muscular dystrophy in Japan: a questionnaire survey based on the Japanese Registry of Muscular Dystrophy (Remudy) ⁷⁶ Ibid.
- 77 New Report Reveals LGBTQ Seniors Face Critical Challenges Accessing Aging Services
- ⁷⁸ Meeting the Health and Social Needs of LGBTQ+ Older Adults Through Medicaid
- ⁷⁹ Social, Economic, and Health Disparities Among LGBT Older Adult

Health-related social needs

Housing

In addition to increases in the number of older adults in the U.S. and income inequality, health-related social needs including housing, nutrition, transportation, and social connection can be used to help categorize and understand the older adult population. U.S. households are aging at a high rate; in 2022 the share of older households increased to 27% from 22% the previous year. This increase is especially pronounced in smaller metros and rural communities with higher concentrations of older adults.⁸⁰ This growth is critical as the nation's oldest adults have significantly less income to spend on housing than their younger counterparts. In 2022, the median household income was \$87,800 for adults ages 50 to 64, and \$54,900 for those ages 65 to 79. In 2021, nearly 11.2 million older adults spent more than 30 percent of household income on housing costs, an all-time high and a significant increase from 2016.⁸¹ The widening wealth and income inequality has exacerbated the need for affordable housing for older adults.

Most older adults live in their own homes and older households tend to have high homeownership rates. While the share of older adults living in multifamily buildings or multigenerational homes has increased in recent decades – approximately 20% of adults ages 65 and older lived with at least one adult relative of another generation in 2021 – the number of older adults living alone still increases with age.⁸² This proportion rises from 25% among those ages 65 to 79 to over 40% among those 80 and over. Notably, there are disparities across racial and ethnic groups in terms of home ownership and home equity. For example, older Black homeowners have the lowest median equity, followed by older Hispanic owners, older Asian owners, and lastly older white owners.⁸³



Currently available assistance including public housing, Housing Choice Vouchers, project-based Section 8 vouchers, and Section 202 Supportive Housing for the Elderly does not fully meet demand. Strikingly, 3.8 million older renter households with very low income who are eligible for federal housing assistance do not receive it and many face waiting lists that can last for years. Moreover, while older adults have a greater need for accessibility features in homes, accessible housing is not always available. Accessibility features, such as walk-in showers and no-step entries into the home can promote independence, a sense of autonomy, the opportunity to age at home, and prevent injury to both residents and their

Nearly half of the homeless population are adults **OVER 50** caregivers. As of 2019, only 47% of those ages 65 to 79 live in homes with basic single-floor living and a no-step entry into the home.⁸⁴ Accessibility needs are greater for people of color, households with low incomes, and renters. Older Black householders and older Hispanic householders report high rates of difficulties entering, navigating, and using their homes, than white householders according to the American Housing Survey.

As a consequence, homelessness among older adults is on the rise. The number of people ages 65 and older experiencing sheltered homelessness increased between 2019-2021 to more than 60,000.⁸⁵ Adults ages 50 and older make up nearly half of the homeless population, and the number of older adults experiencing homelessness is estimated to triple by 2030.⁸⁶ Many older

adults are less technologically adept than their younger counterparts and may have greater mobility needs related to daily living; these elements, coupled with income inequality and a lack of adequate affordable housing contribute to the stark rise of homelessness among older adults. In addition, older adults tend to experience an increase in housing and medical expenses, while their income often remains fixed. For those that have historically been stably housed, a traumatic event like the death of a spouse, divorce, job loss, eviction, or health issues can lead to homelessness.⁸⁷

⁸⁰ Ibid.

- ⁸² Ibid.
- ⁸³ Ibid.
- ⁸⁴ Ibid.

⁸⁶ The Emerging Crisis of Aged Homelessness

⁸¹ Housing America's Older Adults

⁸⁵ https://www.huduser.gov/portal/sites/default/files/pdf/2021-AHAR-Part-1.pdf

⁸⁷ The Causes of Homelessness in Later Life: Findings from a 3-Nation Study

Transportation

Access to safe and reliable transportation is an issue among older adults. According to the American Housing Survey, over half of older adults reported that their neighborhood lacked good public bus, subway, or commuter rail service in 2021.⁸⁸ For older adults who may be unable to safely operate a personal car, the lack of public transportation options can have particularly far-reaching impacts, when compared to other age groups. Lack of access to transportation increases isolation, constrains autonomy, and can increase mobility risk among older adults.

Food insecurity

Food insecurity affects nearly 11.8 million Americans ages 50 and older, a statistic that has increased in recent years by 25% (2021-2022) which reversed a decadelong decline.⁸⁹ A study found that food insecurity rates increased by 10% from young adulthood (ages 18 to 24), to late-midlife (ages 50 to 64) adult populations.⁹⁰ Among older adults, food insecurity is more prevalent among those who are American Indian and Alaska Native, Hispanic, Black, or Native Hawaiian and Pacific Islander; have low educational attainment; have low income; identify as women; live alone; and live in rural areas.⁹¹ Notably, compared to people ages 60 and older, rates of food insecurity among 50 to 59 year olds are higher.⁹² Caregiving responsibilities, economic challenges, and a lack of nutrition programs for this population may be reasons why those ages 50 to 59 experience higher rates of food insecurity.



The health implications of food insecurity can be extreme for older adults. When food insecure, this population is more likely to have chronic health conditions such as diabetes, high blood pressure, congestive heart failure,



asthma, dementia, and depression.⁹³ In fact, even when older adults experience marginal food security – compared to food insecurity – they have significantly higher risk of experiencing poor mental health including anxiety, which shows how crucial nutrition is to older adults' health and wellbeing.⁹⁴

Social connection

Approximately 50% of individuals over the age of 60 are at risk of social isolation and one-third will experience some degree of loneliness later in life. Social isolation and loneliness are associated with a higher risk of dementia and other serious health problems in older adults – while positive social relationships can help older adults live longer, healthier lives.⁹⁵ Health problems and disabling conditions can restrict mobility and interpersonal communication, making social interaction more difficult.⁹⁶ Further, there is commonly a decrease in opportunities for discretionary social contact due to depletion of social network because of death, illness, and retirement.⁹⁷ In addition, older adults' social space may constrict as they age. Older adults are more geographically bound, which

may induct greater dependence on geographically proximate social ties. In comparison, younger adults' social networks tend to be more geographically dispersed.⁹⁸

⁸⁸ Housing America's Older Adults

⁹² Hunger Among Adults Age 50-59 in 2021

97 Ibid.

⁸⁹ Food Insecurity Increased to 1 in 10 Adults Aged 50 and Older in 2022

⁹⁰ Midlife vulnerability and food insecurity: Findings from low-income adults in the US National Health Interview Survey

⁹¹ Food insecurity and health-related quality of life among a nationally representative sample of older adults: cross-sectional analysis

⁹³ Food Insecurity, Memory, and Dementia Among US Adults Aged 50 Years and Older

⁹⁴ Food insecurity and health-related quality of life among a nationally representative sample of older adults: cross-sectional analysis

⁹⁵ Social Isolation and Loneliness in Older Adults

⁹⁶ Aging in Context: Individual and Environmental Pathways to Aging-Friendly Communities

⁹⁸ Aging in Context: Individual and Environmental Pathways to Aging-Friendly Communities

Healthy aging across the lifespan

Health-related social needs in practice: Stella's experiences

Stella is a Black mother of an adult child with a physical disability, who serves as his dedicated caregiver. Her responsibilities include assisting with ADLs and IADLs, in addition to her normal parenting responsibilities. Caregivers often experience physical, financial, and emotional strain, leading to potential functional impairments. In addition, caregivers are at a high risk for loneliness. Stella's role requires her to be physically capable of assisting her child, which could become more challenging as she ages and potentially develops health issues related to her family history of cancer and heart disease. While Stella is currently relatively healthy, she has a family history of cancer and heart disease; preventative measures like prioritizing a nutrient-dense diet and getting regular exercise are critical to addressing her evolving health status. Additionally, Stella is at an increased risk of developing functional impairments as she ages, a common scenario among caregivers who often prioritize their loved ones' needs over their own health.



Meet Stella



"I need healthcare that supports my role as a caregiver, my family history of cancer and heart disease, and provides resources for preventive care. Emotional support is crucial."

- Caregiver to disabled adult child which strains Stella physically, financially, and emotionally
- Part-time work can bring financial instability
- Family history increases her risk for cancer and heart disease, requiring preventive measures
- Social activities, exercise, and a healthy diet improve Stella's well-being

Because of her parenting and caregiving responsibilities, she hasn't worked outside of the home, however, she is beginning to look for part-time work to supplement her family's income. While Stella is currently able to support her son, she may experience financial instability in the future, and her access to stable housing, transportation, nutrition, and social connection may be in jeopardy. As she seeks employment outside the home, she may face additional financial strain in ensuring her son is adequately supported. In addition, this potential shift will likely impact Stella's son emotionally as his dedicated caregiver and daily routine will change.

Despite these challenges, Stella can benefit from protective factors such as engaging in social activities, regular physical exercise, and maintaining a healthy diet, which are essential for preserving cognitive and functional health. Support networks and community resources aimed at caregivers can also provide crucial assistance, allowing Stella to meet her own needs while maintaining her caregiving responsibilities.

Economic needs

Aging adults currently face significant economic challenges, especially regarding retirement savings and health care costs. Many adults between the ages 50 and 64 face high out-of-pocket health care expenses and declining access to employer-sponsored health coverage.⁹⁹ Approximately 20% of adults ages 50 and older have no retirement savings, and over half worry about having enough funds to sustain their retirement.¹⁰⁰ The projected trends suggest a worsening scenario, with the costs of long-term care expected to rise substantially by 2047, making it crucial to develop strategies that ensure financial security and adequate health care for older adults.¹⁰¹

Several positive factors can help strengthen the economic stability of older adults. Phased and flexible retirement arrangements allow workers over the age of 50 to gradually reduce their work hours while maintaining their connection to the workforce. This approach helps retain skilled workers and provides continued income, employer-sponsored health care, and professional development opportunities. Additionally, employer-provided education on financial planning and retirement readiness can equip workers with the necessary information to make informed decisions about their continued employment. These strategies may enhance older adults' ability to manage competing responsibilities and improve their financial security.¹⁰²

AmeriCorps also provides some opportunities for individuals ages 55 and older to reenter the workforce and continue to contribute to their communities. One of these programs is known as the Seniors RSVP, which aims to place older adults into volunteer programs to address critical community needs. Similarly, AmeriCorps offers the Foster Grandparents Program which engages adults ages 55 and above in volunteer service and to provide one-on-one support to children with special needs to improve their academic, social, or emotional development.

One of the primary challenges faced by aging adults is the insufficient retirement savings, compounded by the decline of defined benefit plans and uncertainties surrounding Social Security.^{103,104} Adults ages 50 to 64 face rising out-of-pocket health care costs and declining access to employer-sponsored health coverage. More than three-quarters of individuals purchasing health insurance in the private individual market spend at least 10% of their disposable family income on health care. On average, their spending on premiums was more than 2.5 times higher than those with employer-sponsored coverage.¹⁰⁵ Additionally, the economic impact of caregiving responsibilities can result in substantial financial strain, leading to

To ensure older adults remain economically secure:

- Address age discrimination in the workplace
- Promote flexible work arrangements

increased debt and reduced savings.¹⁰⁶ Addressing these gaps requires targeted policies that provide financial support and affordable health care options for older adults, as well as workplace programs that accommodate their caregiving responsibilities.

⁹⁹ Health Insurance Coverage for 50- to 64-Year-Olds

¹⁰¹ Forbes - Are You Prepared To Live To Be 100?

¹⁰³Longevity Project: Financial Security Pillar

¹⁰⁵ Health Insurance Coverage for 50- to 64-Year-Olds



¹⁰⁰ New AARP Survey: 1 in 5 Åmericans Ages 50+ Have No Retirement Savings and Over Half Worry They Will Not Have Enough to Last in Retirement

¹⁰² Phased Retirement and Flexible Retirement Arrangements: Strategies for Retaining Skilled Workers

¹⁰⁴ HRS - Aging in the 21st Century

¹⁰⁶ Caregiving in the U.S. - AARP Research Report (2020)

Healthy aging across the lifespan

Limited access to affordable health care and the declining availability of employer-sponsored health coverage exacerbate economic challenges for older adults^{107,108} Additionally, the lack of comprehensive social safety nets for childless, non-elderly adults contributes to higher rates of poverty and financial instability later in life.¹⁰⁹ Policy changes that expand Medicare access to those ages 50 to 64, provide better financial support for caregivers, and enhance retirement savings plans could help mitigate these barriers.^{110,111,112,113} Furthermore, addressing age discrimination in the workplace and promoting flexible work arrangements are crucial steps to ensure that older adults remain economically secure and actively engaged in the labor force.^{114,115}

Economic needs in practice: Ryan's experiences

Ryan is an Asian American man in his mid-fifties living with schizophrenia, opioid use disorder, and a history of alcohol abuse. He has endured long periods of homelessness and was recently released from incarceration. Ryan is now beginning to enter a mental health and addiction treatment program, marking a crucial turning point in his life. However, these conditions require continuous and specialized care, leading to substantial out-of-pocket health care expenses. Given his history of homelessness and recent incarceration, Ryan likely lacks employersponsored health coverage, exacerbating his financial burden. However, Ryan could be eligible for Medicaid coverage which may help him navigate the high costs of medication, therapy, and regular medical appointments on his own. Without adequate coverage, these expenses could consume a significant portion of any limited income or savings he might have.



Meet Ryan

"It's tough, but I've got to believe there's a way through it all."

- Asian American, mid 50's
- Living with schizophrenia, opioid use disorder, and a history of alcohol abuse
- · Often homeless and recently incarcerated
- Facing age discrimination, health issues, and gaps in his employment history

Ryan has not had consistent employment due to his health issues, periods of homelessness, and incarceration. Reentering the workforce is challenging for Ryan due to his age, health conditions, and gaps in employment history. Age discrimination and the stigma associated with his medical conditions create additional barriers to finding stable employment. Flexible or supported work arrangements and phased retirement options are vital for Ryan. These would allow him to gradually re-integrate into the workforce, maintain an income, and possibly access employersponsored health care and retirement benefits.

Given his circumstances, Ryan could benefit significantly from care coordination that comes with a Medicaid managed care plan. The care manager may be able to help him navigate his health and social needs. For example, without a permanent address, maintaining employment and accessing necessary services becomes nearly impossible. His managed care plan can help him identify programs that offer subsidized housing and support services tailored to individuals with behavioral health conditions. Additionally, Ryan could participate in a financial education program which may help him understand budgeting, saving, and managing health care costs.

¹⁰⁷ Forbes - Are You Prepared To Live To Be 100?

¹⁰⁸ Health Insurance Coverage for 50- to 64-Year-Olds

¹⁰⁹ We should plug the safety net's biggest hole

¹¹⁰ Medicare for 50-to-64-Year-Olds: Assessing the Effects of Allowing Older Adults to Buy Into the Medicare Program

¹¹¹ Rationalizing a Medicare Buy-In Policy for Adults Ages 50 to 64 That Builds on the ACA

¹¹² New U.S. Workforce Report: Nearly 70% of Family Caregivers Report Difficulty Balancing Career and Caregiving Responsibilities, Spurring Long-Term Impacts to U.S. Economy ¹¹³ HRS – Aging in the 21st Century

¹¹⁴ Age Discrimination Among Workers Age 50-Plus

¹¹⁵ Phased Retirement and Flexible Retirement Arrangements: Strategies for Retaining Skilled Workers

Conclusions

Jerry and Margie's Experiences

Jerry is a white man in his 50s who supports his wife, Margie, and their two young children in a rural community. A few weeks ago, he visited a doctor for the first time in several years after experiencing significant abdominal pain, rapid weight loss, and fatigue. Eventually, after several rounds of tests and specialist visits, Jerry was diagnosed with stage IV pancreatic cancer, and estimated to have less than one year left to live. After receiving this diagnosis, he needed to leave his job to focus on his family and palliative care treatments.

Margie tries to care for him as much as possible but is overwhelmed by his needs on top of caring for their children. While Jerry was able to use the Family and Medical Leave Act (FMLA) to maintain his employer health insurance for 12 weeks, he and his wife aren't sure how they will be able to cope without his income or insurance coverage for the family. Margie wants to hire an aide to come to their home for a few hours a week so she can spend time on other household duties, look for work, or take a break. However, without Jerry's income,



Meet Jerry

"After all these years of working hard and trying to save, it feels like I'm leaving Margie and the kids with nothing but tough choices."

- White man, 50s
- Lives in rural community
- Supports wife and two young children
- Diagnosed with stage IV pancreatic cancer
- Does not qualify for Medicare hospice coverage

they can't afford to pay out of pocket for a helper. Jerry's life savings, the family's cars, and their house all count as assets that places the family well above the Medicaid financial eligibility threshold in their state. Jerry also doesn't yet qualify for Medicare hospice coverage, because his doctor believes he still may potentially live for up to a year.

With Jerry feeling increasingly ill and exhausted, Margie has been left to try and navigate these decisions on her own. She wants to ensure that Jerry is comfortable for his remaining time and needs to protect her family's future. Selling their home and spending their savings could potentially allow her family to qualify for Medicaid to receive the extra in-home support they need over the next few months. But Margie doesn't know what future risks or hardships they would need to navigate after Jerry passes away, or how she will be able to continue to support her children in the long-term without a car, home, or job. Running out of time, money, and options, Margie is at a loss for what to do next.

Anthony, Jane, Stella, Ryan, Jerry, and Margie's stories reflect just a few of the many challenges that Americans ages 50 to 70 are forced to navigate every day. Our health and economic safety net systems operate under mounting resource constraints, trying to serve growing populations of people with complex needs with fewer financial and staffing resources. Consequently, they are constantly triaging and attempting to furnish services to those with the highest needs. For relatively younger individuals with lower overall needs, they are often forced to make do without support, until they reach the age, poverty status, or enter a crisis. By failing to appropriately invest in preventative or early-intervention services for relatively younger populations, our health and social care systems are missing opportunities to leverage relatively low-intensity, low-cost services that can have significant impacts over the course of an individual's aging trajectory. By only waiting to intervene until someone is in crisis, with significant health, functional, and/or social needs, aging systems perpetuate cycles of poverty and disparities that lead to worse aging outcomes.

Appendix

Table 1: Population demographics, U.S. adults ages 50 to 70 and total U.S. population

Characteristic	Adults Ages 50 - 70		Total U.S. Population	
	Number	Percent	Number	Percent
Total Population	80 million	-	330 million	-
Race / Ethnicity				
White	64,640,327	79%	251,602,174	75%
Hispanic	11,206,789	14%	63,664,346	16%
Black or African American	10,050,884	12%	45,399,743	14%
Asian	4,661,482	6%	20,953,941	6%
American Indian / Alaskan Native	875,398	1%	4,382,243	1%
Native Hawaiian/ Pacific Islander	166,257	<1%	878,808	<1%
Two or More Races	1,130,058	1%	10,070,657	3%
Narital Status				
Married	51,0310,000	64%	133,159,000	49%
Divorced	13,354,000	17%	26,016,000	10%
Never Married	10,018,000	12%	92,519,000	34%
Education Level				
Less than High School	7,323,000	9%	37,011,000	13%
High School Degree	24,001,000	30%	74,789,000	27%
Some College	20,617,000	26%	68,313,000	25%
Bachelor's Degree	17,266,000	22%	57,342,000	21%
Advanced Degree	11,061,000	14%	34,076,000	13%
Nativity				
Native U.S. Citizen	65,405,000	81%	281,854,000	85%
Foreign Born	12,863,000	19%	48,778,000	15%
Gender Identity & Sexual Orientation				
Identifies as LGBT (ages 50 -69)	3,513,570	-	19,608,163	
Identifies as Transgender	-	0.3%	-	1.6%
or Nonbinary (ages 50+)				
Employment & Poverty Status				
Employed (ages 50 -64)	42,033,000	68%	160,206,000	96%
Unemployed or Not in Civilian Labor Force (ages 50 - 64)	19,768,000	32%	6,189,000	4%
At or Above Poverty	72,021,000	90%	292,154,000	89%
Below Poverty Level	8,248,000	10%	37,923,000	11%
Disability Status (Ages 60+)				
Ambulatory Disability	14,088,494	18%	20,908,400	7%
Cognitive Difficulty	5,498,218	7%	17,570,100	3%
Hearing Disability	8,591,979	11%	12,049,400	4%
Independent Living Disability	8,596,631	11%	15,786,800	6%
Self-Care Disability	4,594,198	6%	7,977,200	3%
Vision Disability	4,042,159	5%	8,177,000	3%