Addressing Alzheimer's Disease and Related Dementias in the City of Boston

2024 – 2026 Strategic Plan
Boston Public Health Commission

BOSTON PUBLIC HEALTH COMMISSION

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Executive Summary

The Boston Public Health Commission (BPHC) is the local health department for the City of Boston. The U.S. Centers for Disease Control and Prevention (CDC) granted the BPHC a "Core Capacity Award" of $700,000 under the Building Our Largest Infrastructure for Alzheimer's Act (BOLD), Public Law 115-406, for Public Health Programs to Address Alzheimer's Disease and Related Dementias (ADRD) (CDC-RFA-20-2004).

With this award, BPHC launched the BOLD Project on September 30, 2021. Over the two-year funding period, BPHC has worked to build public health infrastructure and advance policy, systems, and environment changes that help Boston residents reduce their risk of Alzheimer's disease and related dementias (ADRD) at every stage of life, access screening and early diagnosis of dementia, and utilize high-quality, culturally and linguistically competent resources and services.

Nationwide, compared to White older adults, African American and Black older adults are twice as likely, and Hispanic and Latino/a/e/x older adults are one and one-half times as like-ly to be diagnosed with Alzheimer's disease or another dementia. There is no genetic basis for these disparities in ADRD risk, which are driven by a long history of systemic racism and structural oppression that put people of color at higher risk of both ADRD and other diseas-es that contribute to ADRD risk. Given these disparities and inequities, BPHC has identified African American, Black, Hispanic, and Latino/a/e/x residents at the highest risk of ADRD as the priority population for the BOLD Project.

BPHC organized the BOLD Citywide Advisory Committee, a multi-disciplinary team of stake-holders and key collaborators who co-led BOLD Project activities from 2021-2023. BPHC and the committee conducted a community needs assessment to better understand the experi-ences, needs, and challenges of people living with ADRD in Boston and those of the direct care workforce that provides critical support to residents with ADRD at home and in the community.

The needs assessment informed the development of the Boston ADRD Strategic Plan – a set of priorities, strategies, objectives, and activities designed to build stronger policies, systems, and supports in Boston for people living with ADRD, their family care partners, and paid caregivers. Over the timeframe from 2024-2026, BPHC aims to develop an implementation plan and along with partners, put the following strategic priorities into action:
1. Finding and Connecting to ADRD Support Services
2. ADRD Family Care Partner Support
3. ADRD Workforce Systems and Capacity
4. ADRD Risk Reduction, Detection, and Early Diagnosis
5. ADRD Surveillance Data Collection

For more information about the Boston BOLD Project or the 2024-2026 Boston ADRD Stra-tegic Plan, contact BOLD@bphc.org.

BACKGROUND

Boston BOLD Project

The Boston Public Health Commission (BPHC) is the local health department for the City of Boston. The U.S. Centers for Disease Control and Prevention (CDC) granted the BPHC a "Core Capacity Award" for $700,000 under the Building Our Largest Infrastructure for Alzheimer's Act (BOLD), Public Law 115-406, for Public Health Programs to Address Alzheimer's Disease and Related Dementias (ADRD) (CDC-RFA-20-2004).

With this award, BPHC launched the BOLD Project on September 30, 2021. Over the two-year funding period, BPHC has worked to build public health infrastructure and advance policy, systems, and environmental changes that help Boston residents:

- Reduce their risk of Alzheimer's disease and related dementias (ADRD) at every stage of life
- Gain knowledge and awareness of the risk factors and early warning signs of cognitive decline and the confidence to talk to their physician about brain health
- Access screening, early detection, and diagnosis of dementia
- Access and utilize culturally and linguistically appropriate caregiving services and supports in their local communities
- Find resources that support financial and overall health and well-being if they are caring for someone with dementia

Using key public health strategies – education and empowerment, workforce capacity building, partnership building, and strong data surveillance – BPHC's Boston BOLD Project aims to ensure that all residents, particularly those who are at the highest risk of ADRD and bearing the largest burden of ADRD caregiving, can navigate the experience of dementia with greater ease, access, and support.

Key Deliverables

To kick off the BOLD Project, BPHC formed the **Boston BOLD Citywide Advisory Committee** – a multidisciplinary stakeholder group comprised of family caregivers, social services providers, medical providers, researchers, and community leaders who are vital partners in public health infrastructure -building efforts to address ADRD.

Together with BOLD Project team leads, the **Advisory Committee** helped conduct an **ADRD Needs Assessment** and with other stakeholders, helped shape the content and priorities outlined in this **Strategic Plan**.

See Appendices C, D, and E for lists of BOLD Citywide Advisory Committee members and contributors to the BOLD needs assessment and Boston ADRD Strategic Plan.
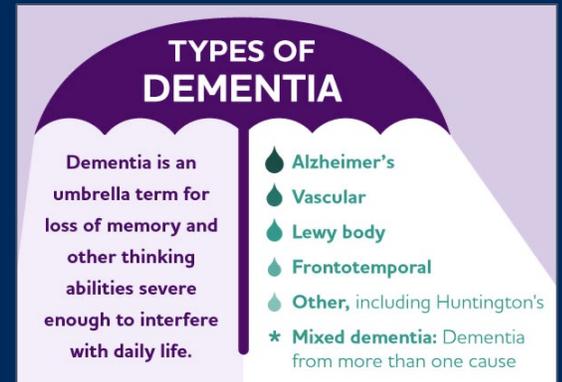
Boston's Demographics and Aging Population

The city of Boston is home to about 650,000 residents, of whom 23.5% identify as Black or African American; 19.8% identify as Hispanic and/or Latino/a/e/x; 9.7% identify as Asian; and 44% identify as non-Hispanic white. Nearly 12% of Bostonians – more than 81,000 – are over age 65, and among these older adults, 26% identify as Black or African American, and 11% identify as Hispanic and/or Latina/o/e/x.[1]

Boston is projected to have over 100,000 residents age 65 or older by 2030.[2] The Massachusetts Healthy Aging Collaborative estimates that about 16% of Bostonians age 65 and up, or almost 13,000 residents, currently have a dementia diagnosis and by the end of this decade, that figure, is expected to grow to 20,000 Bostonians living with ADRD.[3] With a growing older population, Boston has sought to become more age-friendly, and addressing Alzheimer's disease and related dementias is an important strategic priority for the city.

ALZHEIMER'S DISEASE AND RELATED DEMENTIAS

Dementia: an Umbrella Term for Several Pathologies

According to the Alzheimer's Association, "dementia is a general term for symptoms that may include loss of memory, language, problem-solving and other thinking abilities that are severe enough to interfere with daily life." There are several common causes of dementia, including Alzheimer's, vascular dementia, Lewy body dementia, frontotemporal degeneration, hippocampal sclerosis, and Huntington's dementia. Each type has a unique pathology and leads to various cognitive, mental, behavioral, and physical symptoms. Individuals may experience a singular type of dementia or experience pathologies associated with multiple types, as in cases of mixed-cause dementia. Dementia is usually progressive and, so far, incurable, leading to a loss of independence as the disease worsens over time.

TYPES OF DEMENTIA

Dementia is an umbrella term for loss of memory and other thinking abilities severe enough to interfere with daily life.

- Alzheimer's
- Vascular
- Lewy body
- Frontotemporal
- Other, including Huntington's
- * Mixed dementia: Dementia from more than one cause
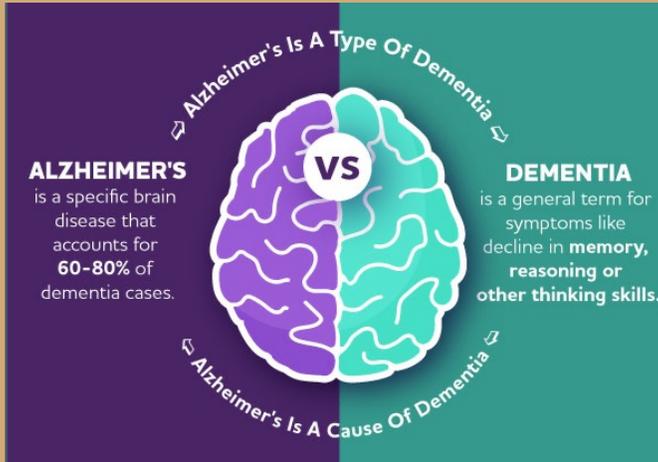
Alzheimer's Dementia

Alzheimer's is the most common cause of dementia, and most people (60-80%) who have dementia have the type known as "Alzheimer's disease."[5] In 2019, Alzheimer's disease was the sixth leading cause of death in the U.S.[6], and dropped to the seventh leading cause in 2020 and 2021 with the emergence of the COVID-19 pandemic.

As of 2023, an estimated 6.7 million people in the United States are living with Alzheimer's dementia, and the prevalence is projected to rise to more than 16 million Americans by 2026.[7]

ADRD Disparities and Inequities

While the risk of dementia increases with age for all individuals, risk is not distributed equally across race, ethnicity, sex, or sexual orientation. Measurement of risk – or incidence – of Alzheimer's disease and other dementias is complex and varies from study to study, complicated by populations' vast diversity in culture, context, and health status. However, there are marked disparities in ADRD burden – or prevalence – among Black, Hispanic, and Latino/a/e/x older adults compared to White older adults in the U.S. Disparities in ADRD lifetime risk and, prevalence – and the underlying inequities rooted in structural racism – serve as an urgent call to action to center health equity and racial justice as we confront ADRD at every level of prevention and treatment.

Based on current research on the prevalence and incidence of Alzheimer's disease and other dementias, about 1 in 9 people (10.7%) age 65 and older in the US has Alzheimer's dementia, with that prevalence increasing with age. Data from the Framingham Heart Study estimates the lifetime risk for Alzheimer's dementia and other dementias at age 45 to be about 1 in 5 (20%) for women and 1 in 10 (10%) for men, the risk for both growing slightly after age 65.[8]

Importantly, studies also indicate that older Black individuals are about twice as likely, and older Hispanic individuals are about one and a half times as likely to have Alzheimer's or other dementias compared to older White individuals. Some estimates project that

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[5] Alzheimer's Association. What is dementia? https://www.alz.org/alzheimers-dementia/what-is-dementia.
[6] UsAgainstAlzheimer's. The Alzheimer's Disease Crisis – By the Numbers. https://www.usagainstalzheimers.org/learn/alzheimers-crisis.
[7] Matthews KA, Xu W, Gaglioti AH, Holt JB, Croft JB, Mack D, McGuire LC. Racial and ethnic estimates of Alzheimer's disease and related dementias in the United States (2015-2060) in adults aged ≥65 years. Alzheimers Dement. 2019 Jan;15(1):17-24. doi: 10.1016/j.jalz.2018.06.3063. Epub 2018 Sep 19. PMID: 30243772; PMCID: PMC6333531.
[8] Alzheimer's Association. 2023 Alzheimer's Disease Facts and Figures. Alzheimers Dement 2023;19(4). DOI 10.1002/alz.13016.
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between 2020 and 2060, ADRD prevalence in the U.S. could increase the most among Hispanic and Latino/a/e/x older adults and African American adults aged 65 years and older compared to other race and ethnicity groups. Over the next 40-years, ADRD is projected to increase by 70% among White older adults, double among African American older adults, and quadruple among Hispanic and Latino/a/e/x older adults, barring the development of medical breakthroughs to prevent, slow, or cure ADRD.6

Furthermore, the U.S. older adult population includes millions of lesbian, gay, bisexual, and transgender (LGBT) people. Researchers estimate that there are 2.7 million LGBT people over age 50, and that number is increasing rapidly as more people self-identify as LGBT. LGBT people are within every community, and the LGBT older adult population is one of tremendous racial, ethnic, cultural, and religious diversity. For example, one in five (20 percent) of LGBT older adults are people of color. To that end, BPHC is committed to addressing the many challenges and needs that LBGT older adults and their caregivers face living with dementia, particularly those disadvantaged by intersecting and historically oppressed identities.[9]

These racial/ethnic disparities have remained consistent over time in the U.S. and do not reflect the effect of genetics on risk. Research suggests these disparities are rooted in the historic and continued marginalization of Black and Hispanic populations in U.S. society. In turn, this negatively impacts the social and physical environments and individual experiences across their life course, increasing the risk of chronic conditions, which are associated with a higher risk of dementia and complicated dementia, including cardiovascular disease and diabetes.

Additionally, structural barriers to ADRD screening influence when and whether individuals receive a diagnosis and subsequent care. Evidence shows that delayed and missed dementia diagnoses are more common among Black, African American, and Hispanic older adults than among White older adults, suggesting that studies estimating burden based solely on utilization of health care underestimate racial and ethnic disparities in ADRD prevalence.[10]

See the Alzheimer's Association's 2023 Facts and Figures Report for an in-depth discussion of current trends in the epidemiology of Alzheimer's and dementia.

[9] Flatt JD, Johnson JK, Karpiak SE, et al. Correlates of subjective cognitive decline in lesbian, gay, bisexual, and transgender older adults. J Alzheimer's Dis. 2018;64(1):91-102. doi. org/10.3233/JAD-171061 41. Gordon K, McGinn-Shapiro M, G
[10] Alzheimer's Association. 2023 Alzheimer's Disease Facts and Figures. Alzheimers Dement 2023;19(4). DOI 10.1002/alz.13016.

Dementia Risk Factors

The strongest risk factor for dementia is age, and most people who develop Alzheimer's dementia are over the age of 65, and the risk rises with age: the most recent data show that 5.0% of people aged 65 to 74, 13.1% of people aged 75 to 84, and 33.3% of people over age 85 have Alzheimer's dementia.[11] Genetics also influence risk and age of onset in people who develop dementia, as well as having a family history, particularly among close relatives such as parents and siblings. Age, genetics, and family history are *non-modifiable* risk factors.

There are 12 modifiable risk factors that if addressed throughout the lifespan at the population level may prevent up to 40% of dementia cases within the U.S. in the coming decades,[12] representing a major opportunity for public health departments to intervene. These risk factors are:[13]

Early Life (age < 45 years):
- education

Midlife (age 45-65 years):
- hearing loss
- traumatic brain injury (TBI)
- hypertension
- excessive alcohol consumption
- obesity

Later Life (age > 65 years):
- smoking
- depression
- social isolation and cognitive engagement
- physical inactivity
- diabetes
- air pollution

The environments, systems, and structures in which individuals and populations live, work, learn, and age – their social determinants of health – can also influence dementia risk. Like the 12 modifiable risk factors, the social determinants of health may be addressed and improved through public health interventions that center on health equity. Research has shown associations between cognition, ADRD risk, and social determinants of health including:

- lower socioeconomic status
- lower education level
- employment in manual labor
- early and late life food insecurity
- early-life adversity
- higher levels of stress
- racial discrimination (both individual and structural)

As with disparities in ADRD prevalence nationwide, the structures and systems that perpetuate racism and health inequities also influence the social determinants of health. To mitigate the impact of ADRD in the coming decades, approaches to building public health infrastructure must center on health equity and racial justice to have a meaningful impact on reducing the risk and burden of ADRD at the population level.

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[11] Alzheimer's Association. 2023 Alzheimer's Disease Facts and Figures. Alzheimers Dement 2023;19(4). DOI 10.1002/alz.13016.
[12] Iibid.
[13] Livingston, G., et al. Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. Lancet 2020;396(10248). DOI 10.1016/S0140-6736(20)30367-6.

ALZHEIMER'S AND DEMENTIA IN THE CITY OF BOSTON

Cognitive Decline, Hospitalization, and Mortality Due to ADRD

Based on the most recent Medicare claims data, City of Boston residents over age 65 have an estimated ADRD prevalence rate of 15.8%, which is higher than the rate of 13.6% for Massachusetts overall.[14] There is not yet true ADRD prevalence or incidence for all residents, nor has there been consistent, population-level measurement of the burden and impacts of ADRD caregiving on Boston residents. Given known inequities in access to dementia screening and early diagnosis, these figures likely underestimate the true prevalence of ADRD.

Despite gaps in our city-level prevalence and incidence data, there is evidence that the racial and ethnic disparities in ADRD risk, prevalence, and caregiving playing out at the national level also exist here in Boston. The next three graphics show 2020 ADRD hospitalization and mortality data from the MA Center for Health Information and Analysis acute hospital case mix database alongside demographic data from the 2015-2019 American Community Survey.
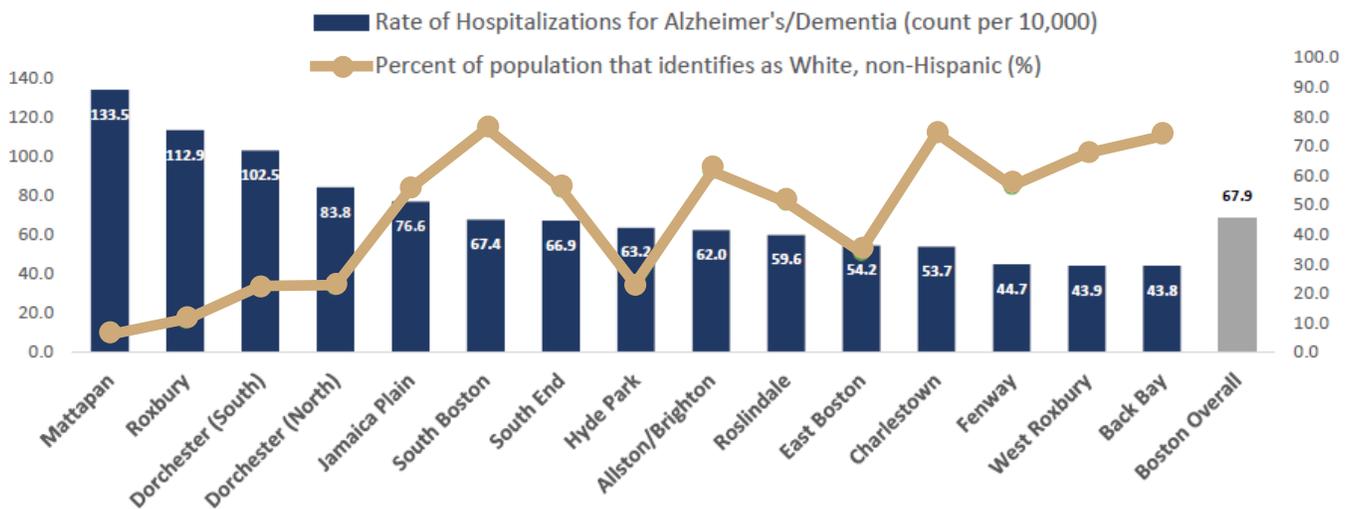
At the neighborhood level, hospitalizations due to Alzheimer's and dementia are highest in Mattapan, Roxbury, and Dorchester, and lowest in Fenway, West Roxbury, and Back Bay.[15]

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[14]*MA Healthy Aging Collaborative. Massachusetts Healthy Aging Report – Community Profile: Suffolk County. 2018. https://ma healthyagingcollaborative.org/data-report/.*
[15]*Hospitalization data - Acute hospital case mix database, Massachusetts Center for Health Information and Analysis (2020); Demographic data - U.S. Census Bureau, American Community Survey, BPDA Research Division Analysis (2015-2019); Note: hospitalization rates shown are age-adjusted*

Alzheimer's/Dementia Mortality Rate (count per 100,000)
Percent of population that identifies as White, non-Hispanic (%)

	Roslindale	Roxbury	Mattapan	South Boston	West Roxbury	Jamaica Plain	Dorchester (South)	Dorchester (North)	Hyde Park	Charlestown	Allston/Brighton	South End	Fenway	Back Bay	Boston Overall
Mortality Rate	42.5	33.0	31.2	27.0	22.9	21.5	20.5	18.5	16.6	13.9	11.0	9.3	7.5	6.2	16.8
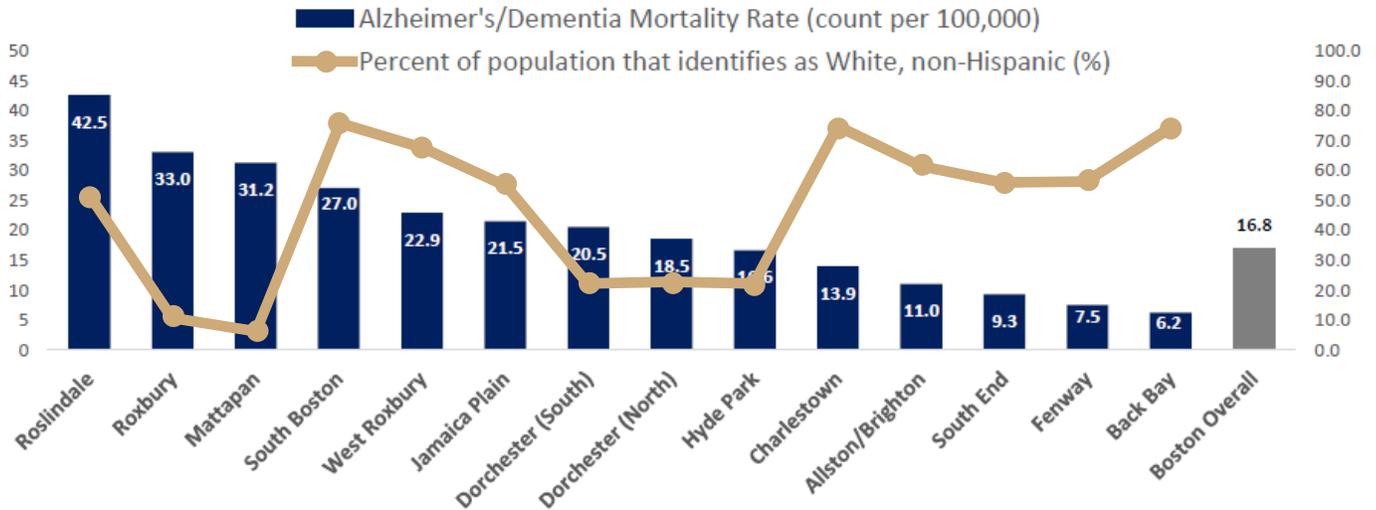
Mortality rates for Alzheimer's and other dementias are highest in Roslindale, Roxbury, and Mattapan, and lowest in South End, Fenway, and Back Bay.[16]

Rate of Hospitalizations for Alzheimer's/Dementia (count per 10,000)
Alzheimer's/Dementia Mortality Rate (count per 100,000)

	Black	Hispanic/Latino	White	Asian
Rate of Hospitalizations	109.5	69.2	57.5	32.0
Mortality Rate	22.7	23.2	17.3	5.5
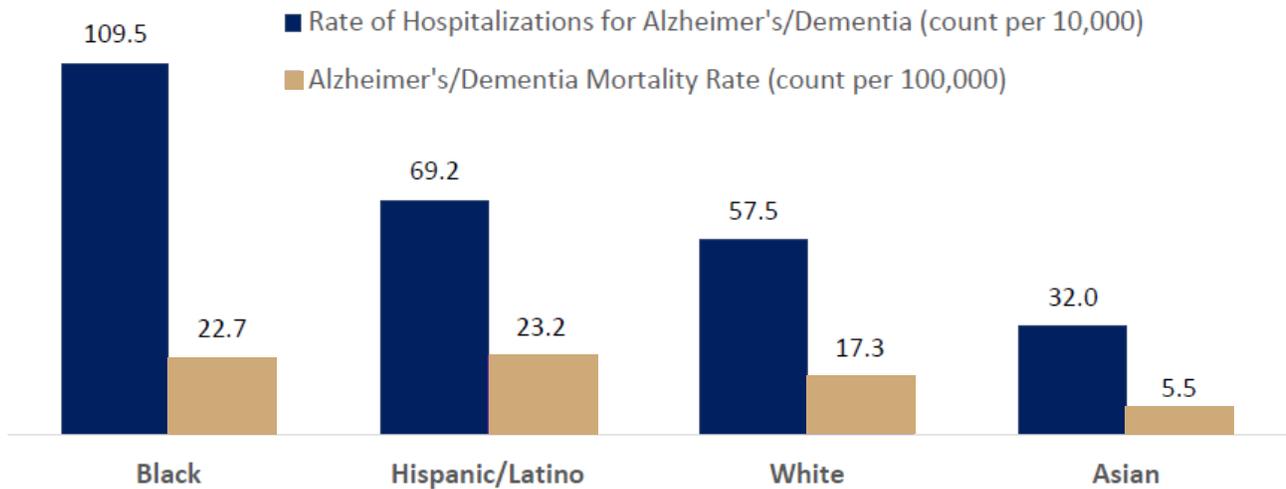
Among all Boston residents, those who identify as Black have the highest rate of hospitalizations due to Alzheimer's or other dementia compared to other races and ethnic groups. Both Black and Hispanic residents have higher rates of mortality due to ADRD compared to other groups.[17]

While we cannot conclusively know if the higher versus lower rates of hospitalizations and mortality for Alzheimer's and other dementias align with actual prevalence and incidence, the figures above do illustrate that hospitalizations and mortality align with the racial and ethnic disparities in ADRD prevalence seen nationwide.

[16]HRiA, BPHC. BOLD Needs Assessment Data Brief: Prevalence of Alzheimer's/Dementia and Related Risk Factors among Boston Residents. 2022.
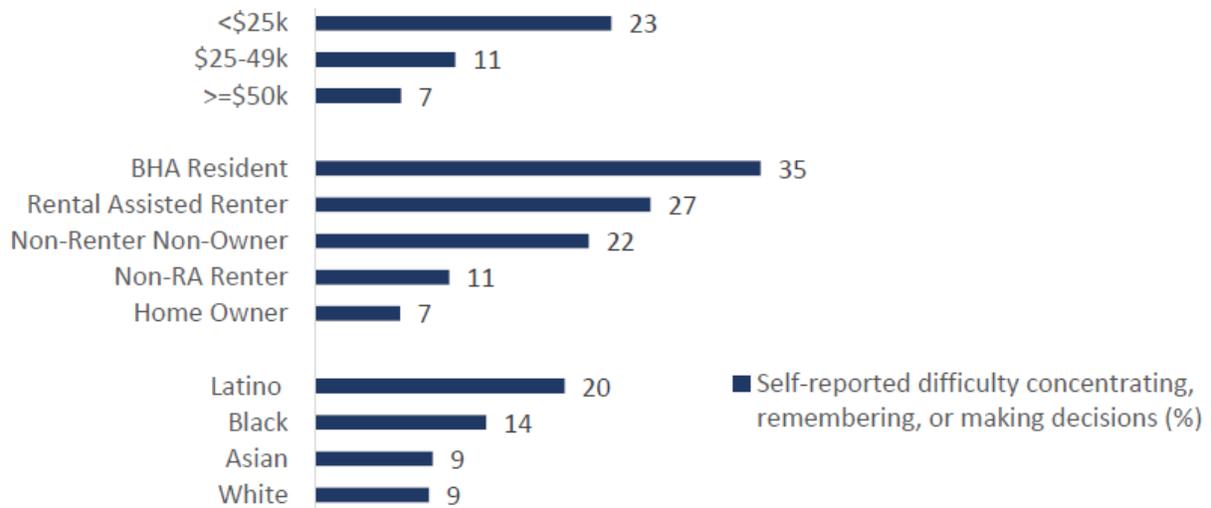[17]Hospitalization data - Acute hospital case mix database, Massachusetts Center for Health Information and Analysis (2020); Demographic data - U.S. Census Bureau, American Community Survey, BPDA Research Division Analysis (2015-2019); Note: hospitalization rates shown are age-adjusted

Self-Reported Cognitive Impairment Among Boston Residents

Data gathered through the Boston Behavioral Risk Factor Surveillance System (BBRFSS), conducted in 2019, showed that there are also racial, ethnic, and socioeconomic disparities in perceptions of memory loss.

What is BBRFSS?

The Boston Behavioral Risk Factor Surveillance System (BBRFSS) is a bi-annual phone survey modeled after the national CDC BRFSS of a sample of Boston residents. The survey asks about abut health topics including chronic disease, access to care, and behaviors that impact health, and factors that influence health, such as income, housing, education, and racism.

	Self-reported difficulty concentrating, remembering, or making decisions (%)
<$25k	23
$25-49k	11
>=$50k	7
BHA Resident	35
Rental Assisted Renter	27
Non-Renter Non-Owner	22
Non-RA Renter	11
Home Owner	7
Latino	20
Black	14
Asian	9
White	9

Self-reported difficulty concentrating, remembering, or making decisions is highest among residents who identify as Latino or Black, those who live in public housing, and those who earn less than $25,000 per year.[18]

Additional data from the Boston BOLD Needs Assessment appears later in this strategic plan, alongside the priorities, objectives, and success measures developed to address the gaps, issues, and disparities identified through the Needs Assessment.

[18]*Self-report data - Boston Behavioral Risk Factor Surveillance System, Boston Public Health Commission, data reflect 2019; Note: data reflect responses among all Boston adults*

STRATEGIC PLANNING PROCESS

Alzheimer's, Dementia, and Public Health

The goal of the Boston BOLD Project – and of local and state health departments funded through the CDC's Healthy Brain Initiative (HBI) – is to build public health infrastructure for Alzheimer's disease and related dementias. While the health care system provides treatment after a diagnosis, the public health system uses a variety of approaches to reduce people's risk of disease, and ensure access to screening, diagnosis, and supports, on a population level – ideally before disease onset. Health issues become *public health* issues when three criteria are met: the burden is large, the impact is major, and the response requires collaborative, sustainable, systems-level approaches. Alzheimer's disease and related dementias pose big and complex challenges to individuals, families, and communities, which means public health as an opportunity to intervene. In designing and implementing this strategic plan, BPHC's goal is to build strong public health infrastructure for responding to the rise in ADRD prevalence and the inequities in ADRD risk, caregiving, and cost.

Through a collaborative effort, the CDC along with the Public Health National Center for Innovations and the de Beaumont Foundation convened a task force and developed a framework called the *10 Essential Public Health Services*, designed to "protect and promote the health of all people in all communities.

STRENGTHEN PARTNERSHIPS AND POLICIES:
Public health strengthens, supports and mobilizes community partnerships to improve brain health. It also creates, champions and implements supportive policies and plans.

MEASURE, EVALUATE AND UTILIZE DATA:
Public health monitors health status to identify and solve community health problems and evaluates effectiveness, accessibility and quality of personal and population-based health services. Findings are translated into data-informed programs and policies to improve brain health across the life course.

BUILD A DIVERSE AND SKILLED WORKFORCE:
Public health trains and prepares the public health and health care workforce to educate their constituents and provide the best care to people at risk for or living with dementia while supporting caregivers.

ENGAGE AND EDUCATE THE PUBLIC:
Public health engages with diverse communities to understand how messages are best delivered and what information to convey to specific populations. Public health communicates effectively to educate people about factors that influence brain health and ways to maintain or improve their cognitive health and quality of life.

The CDC created a framework called the *10 Essential Public Health Services*, designed to "protect and promote the health of all people in all communities."

The *Services* set objectives for data collection, evaluation and assessment, policy development, and public health workforce capacity building. Actions advance equity by promoting healthy environments and degrading systemic and structural barriers to good health.

The *10 Essential Public Health Services* guide the CDC's approach to Alzheimer's disease and related dementias. Through its Healthy Brain Initiative, the CDC regularly publishes updates to the "Healthy Brain Initiative Roadmap", a collection of evidence-based, action-oriented strategies that state and local health departments can follow when building public health infrastructure to address Alzheimer's disease and related dementias.
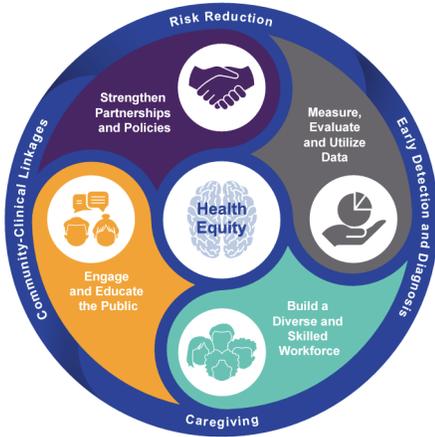
The Road Map addresses four domains that draw on the *10 Essential Public Health Services*. Equity stands at the center of the HBI Road Map framework, which encourages state and local health departments to address social determinants of health.

BPHC's strategic plan aligns with the domains and strategies outlined the HBI Road Map. By applying the Healthy Brain Initiative's *Road Map* framework, the Boston ADRD Strategic Plan aims to:

• Help to reduce racial disparities in the risk of ADRD among Boston's African American, Black, Hispanic and Latino/a/e/x residents.
• Improve residents' access to dementia screening and diagnosis as early as possible in the progression of their cognitive decline.
• Expand access to supports and resources for care partners to Boston residents living with ADRD.
• Establish community-clinical linkages that improve the coordination and continuity of care through every stage of dementia.

Language Note: In this plan, the term "care partner" refers to anyone who provides *unpaid* care for someone who is living with ADRD, while the term "caregiver" refers to *paid* care providers who deliver medical care or social supports to people living with ADRD and their care partners.

Gathering Data

From March – August 2022, BPHC set out to better understand the strengths and challenges of Boston's public health infrastructure around ADRD. In partnership with non-profit consulting firm Health Resources in Action (HRiA), BPHC and the BOLD Advisory Committee conducted a **community needs assessment**, gathering input from a wide range of stakeholders on the needs of people affected by ADRD and their families, as well as the needs of the direct caregiving workforce.

The needs assessment included a literature review of local, state, and national reports and frameworks on ADRD, aging, and equity. BPHC's Center for Public Health Science, Technology, and Innovation compiled surveillance, case mix, and vital statistics data, as well as self-reported data from the Boston Behavioral Risk Factor Surveillance System (BRFSS). Data spanned the period from 2018-2022, and for this analysis data were stratified by age, race, ethnicity, income, housing type, neighborhood, and dual Medicare/Medicaid eligibility.

Together with HRiA, BPHC conducted 17 stakeholder interviews with representatives from community health centers, aging services access points, government agencies, Massachusetts' largest healthcare workers union, medical and social services providers, and community-based leaders. BPHC also hosted two listening sessions with family care partners, and distributed an electronic survey (in English, Spanish, and simplified Chinese) to social services providers for adults over age 65 who are low-income, non-English speaking, and/or identify as African American, Black, Hispanic, Latino, or Asian, including some who have an ADRD diagnosis.

Assessment Methods
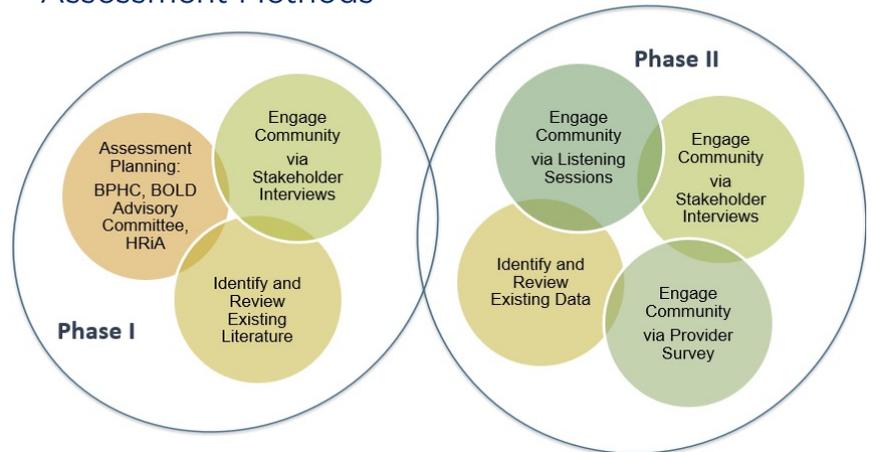
Health Resources in Action: BOLD Needs Assessment Framework

As part of the BOLD needs assessment, BPHC reviewed a range of age and dementia friendly plans and initiatives. Together with partners, BPHC is working to bring public health infrastructure-building initiatives into alignment with aging and ADRD efforts at the city, state, and national levels.

City and State Age and Dementia Plans	National ADRD Initiatives
• Massachusetts ADRD State Plan • Age-Friendly Massachusetts Action Plan: *ReiMAgine Aging* • City of Boston Age Friendly Plan	• Healthy Brain Initiative 2023-2027 Road Map • National Alzheimer's Project Act of 2011 • RAISE (Recognize, Assist, Include, Support & Engage) Family Caregivers Act of 2017

HRiA summarized the key findings in **four data briefs** focusing on:

1. Prevalence of Dementia and Related Risk Factors
2. Needs of Older Adults
3. Experiences of Caregivers
4. Capacity of the Social Services Sector

Themes that emerged from needs assessment findings were used to identify priorities, as well as to inform the goals, objectives, and strategies for the strategic plan. Key data points from each brief are presented here alongside the corresponding priorities. *Visit www.Boston.gov/bphc-brainhealth to see the four needs assessment data briefs.*

Building the Strategic Plan

The **BOLD Advisory group set strategic planning priorities** after reviewing 11 key themes from the community assessment for their relevance, appropriateness, impact, and feasibility. BPHC convened 36 subject matter experts, health policy experts, physicians, social services providers, and caregivers from 18 organizations for a day-long, intensive strategic planning session in November 2022. Over the course of the session, stakeholders gathered in small and large group formats to develop goals, objectives, potential success measures, strategies, and potential partners for each priority.

See Appendices B and C for a full list of contributors to the BOLD Needs Assessment and Strategic Planning Session.

Strategic Plan Elements

The Boston ADRD Strategic Plan addresses five key priorities:

1. Finding and Connecting to Support Services
2. Care Partner Support
3. Workforce Systems and Capacity
4. Risk Reduction, Early Detection, and Diagnosis
5. Survelliance Data Collection

> ➤ *Priorities* are critical issues or challenges that provide a focus for planning.
>
> ➤ *Goals* are broadly stated, non-measurable changes or results in the priority area.
>
> ➤ *Objectives* articulate goal-oriented outcomes that are SMART-E (specific, measurable, achievable, relevant, time-phased, and equitable).
>
> ➤ *Strategies* describe how an objective will be achieved.
>
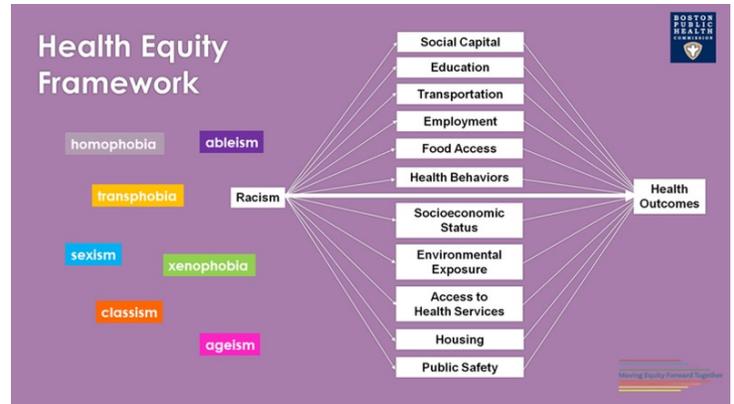> ➤ *Success* measures are measure(s) of progress toward the objective.

BPHC's strategic plan centers equity as a cross-cutting theme, in alignment with core organizational priorities of racial justice and health equity.

BPHC acknowledges that structural oppression in the form of racism, classism, transphobia, homophobia, sexism, ableism, ageism, and xenophobia negatively impact communities' social determinants of health (SDOH) and health outcomes, including the risk for Alzheimer's disease and related dementias, chronic diseases like diabetes and hypertension that increase ADRD risk, and access to supports and services for screening, diagnosis, and caregiving. Importantly, exposure to structural racism throughout the lifespan compounds dementia risk at every stage of life.

Given the racial and ethnic disparities in ADRD risk, and in the burden of ADRD morbidity and mortality in Boston, BPHC will focus on African American, Black, Hispanic, and Latino/a/e/x residents at highest risk for ARDR and related risk factors – and bearing the largest burden of caregiving – through the BOLD Project and the activities outlined in this strategic plan.

BPHC *Office of Racial Equity and Community Engagement*: Health Equity Framework

What are SDOH?

According to the World Health Organization, social determinants of health are "the non-medical factors that influence health outcomes. They are the conditions in which people are born, grow, live, and age, and the wider set of forces and systems shaping the conditions of daily life."

BPHC intentionally centered equity in designing the Boston BOLD project by recruiting partners across many sectors including direct service providers, faith- and community-based organizations, an African American family caregiver, local government partners, major hospitals, and community health centers that serve the project's priority populations. When implementing this plan, BPHC will work to put equity into practice by:

- Organizing an *equity in implementation* working group
- Engaging, recruiting, and uplifting organi ǂzational partners who serve the project's priority populations
- Ensuring communications materials are culturally appropriate and available in multiple languages

- Evaluating the impact of BOLD Project programs on the priority populations
- Partnering with trusted community leaders and representatives to disseminate information about ADRD
- Ensuring that input from people living with ADRD and their care partners is centered and put into action

PRIORITY 1: FINDING AND CONNECTING TO SUPPORT SERVICES

Data Highlights

According to BPHC's 2022 survey of Boston-area social services providers, older adults with dementia have the greatest need for:

- safe and accessible housing
- transportation to and from care appointments
- help paying for basic needs and services
- case management and care coordination

Barriers to Support

Prevention
- Lack of awareness of prevention strategies across the lifespan
- Food insecurity, housing instability, lack of access to green space
- Lack of transportation to medical appointments and difficulty managing chronic diseases

Screening and Diagnosis
- Lack of awareness of early warning signs
- Perception of memory loss as normal aging
- Difficulty getting medical appointments

Post-Diagnosis
- Lack of awareness of available services
- Services are not culturally competent

GOAL:

Boston residents who are at risk of Alzheimer's disease or a related dementia, and those who receive a dementia diagnosis, are aware of, access, and utilize services and supports.

The needs of older adults living with ADRD are complex and require a range of supports. Through a survey of social services providers and a series of listening sessions with care partners, BPHC set out to better understand the care and support needs of older adulting living with ADRD in Boston.

Care partners from East Boston, Dorchester, Hyde Park, Mattapan, Roslindale, Roxbury, and West Roxbury joined BPHC's listening sessions. The BOLD provider survey drew responses from social services providers working with low-income Black, African American, Hispanic, Latino/a/e/x, and Asian older adults, the majority of whom have clinically diagnosed Alzheimer's or another dementia.

BPHC learned that while the City of Boston has organizations and collaborations providing support services, residents often face barriers to access, including low awareness of programs, complex eligibility requirements, lack of coordination between healthcare and social service providers, and strict insurance requirements to obtain specialized care.[19]

To better support older adults at risk of or living with ADRD, social services providers and care partners called for community-based education and empowerment, better access to screening, and revised policies around the cost and coverage of dementia care. Care partners highlighted the need for culturally and linguistically responsive information about where and how to find and enroll in dementia and care partner support services.

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[19]HRiA, BPHC. BOLD Needs Assessment Data Brief: Ability of the Social Service Sector in Boston to Meet the Needs of Older Adults. 2022.

Priority 1: Objectives and Strategies

Objective 1.1	Increase awareness of and access to ADRD supports available to Boston residents.
1.1.a.	Develop and implement ongoing, evidence-based, multi-lingual, multi-channel public awareness campaigns on ADRD topics.
1.1.b.	Develop and implement a community engagement plan for grassroots dissemination of ADRD information through place-based, faith-based, government agencies, community-based, and small business networks.
1.1.c.	Organize a network of people living with dementia and their care partners to serve as community ambassadors, peer educators, and collaborators in planning, communications, and community engagement efforts.
Objective 1.2	Increase connection and collaboration between of community-based social services providers, community-based organizations, and dementia care coordination resources.
1.2.a.	Convene a social services provider working group to facilitate collaboration and information sharing.
1.2.b.	Develop and pilot web-based tools to increase communication and collaboration between social services providers.
1.2.c.	Incorporate community-based arts, culture, fitness, and wellness organizations into social services provider working group to support outreach, engagement, and education within specific racial, cultural, and linguistic sub-populations.
1.2.d.	Promote age and dementia-friendly public housing design and adaption to help residents with dementia age in place.
Objective 1.3	Improve access to and utilization of health care coverage and benefits for older adults and people living with ADRD.
1.3.a	Promote enrollment into health care coverage among Boston residents at highest risk for ADRD.
1.3.b	Promote the use of the Medicare Welcome Benefit, specifically cognitive assessment and care planning services covered under Medicare Part B.
1.3.c.	Promote utilization of resources for long-term care directives and financial planning.
Objective 1.4	Advance policy and systems changes that improve dementia care coordination infrastructure and the affordability and accessibility of dementia support services.
1.4.a.	Educate community advocates, city- and state-level policymakers about the needs and experiences of people living with ADRD.
1.4.b.	Educate community advocates, city- and state-level policymakers about the benefits and potential impacts of improving the affordability and accessibility of dementia care and support services.
1.4.c.	Promote the inclusion of community-based supports and referrals in discharge instructions included in electronic medical records at the point of dementia diagnosis.

Success Measures:

- Communications campaigns generate increased engagement year-over-year
- ADRD social services providers join the BOLD working group and use web-based tools
- Increases in Medicare Welcome Benefit usage
- All city- and state-level policymakers receive ADRD education

Partners & Resources:

- Age Strong Commission
- Aging Services Access Points
- Alzheimer's Association
- Minority-owned small businesses
- Boston Medical Center
- Boston Housing Authority
- Print, digital and radio outlets

PRIORITY 2: CARE PARTNER SUPPORT

GOAL:

Care partners to Boston residents living with Alzheimer's Disease and Related Dementias have access to and utilize timely, reliable, and culturally and linguistically responsive supports and resources.

Data suggest that in the U.S., 83% of the help provided to older adults currently comes from unpaid care partners, specifically family members or friends. Nearly half of care partners in the US are caring for someone with ADRD.[20]

Care provided to people with ADRD is complex, including self-care, monitoring medication and treatment adherence, managing behavioral symptoms and comorbidities, providing emotional support, and finding and managing healthcare support services.

The experience of caregiving places physical and mental strain on care partners, putting them at a higher risk for depression, anxiety, disease, and health complications. Care partners for loved ones with ADRD can experience social isolation[21] and significant emotional and financial stress as they navigate complex healthcare and social service systems and provide support through the stages of ADRD progression.

Disparities and inequities by race and ethnicity play out among care partners, as well. In the U.S., Black, Hispanic, and Asian American care partners to people with dementia report experiencing higher care demands, lower access to outside and social support, and a higher likelihood of having depression compared to white care partners.[22]

In a series of listening sessions with care partners to Boston residents living with ADRD, many participants called for better access to screening and diagnosis, noting years often passed between the time they noticed their loved ones' symptoms of

Data Highlights

In 2019, 27% of Boston residents reported having caregiving responsibilities for an adult.

Care partners to older adults or adults with a disability are likelier to live in Dorchester, Hyde Park, Roxbury, the South End, and Mattapan.

Rates of caregiving are highest among:

- Lower-income households (<$49K annual household income)
- Rental-assisted renters
- Black adults
- Hispanic and Latino/a/e/x adults

"I don't know what to do other than put my hands in the air and scream, 'HELP!'"

"It doesn't do anybody any good to tell people about support groups if there is no group in their native language."

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[20]Alzheimer's Association. 2022 Alzheimer's Disease Facts and Figures. Alzheimer's Dement 2022;18.

[21]Hajek, A., Kretzler, B., and Konig, H. "Informal Caregiving, Loneliness and Social Isolation: A Systematic Review." Int J Environ Res Public Health. 2021 Nov 18;18(22):12101. doi: 10.3390/ijerph182212101.

[22]Alzheimer's Association. 2023 Alzheimer's Disease Facts and Figures. Alzheimers Dement 2023;19(4). DOI 10.1002/alz.13016.

their loved one's symptoms of cognitive decline and the point at which they received a diagnosis. Some care partners shared that stigma around openly discussing memory loss prevented them from seeking help sooner, while others admitted they were unaware of where to seek help, both before and after their loved was diagnosed.

After diagnosis, care partners described challenges in accessing and paying for coordinated care that progress along with their loved one's disease. As dementia progresses, care partners cited the critical need for more awareness about programs and services, intensive case management and care navigation supports, and access to services within their local communities and neighborhoods.

Priority 2: Objectives and Strategies

Objective 2.1	Increase awareness of care coordination, case management, and care partner supports among individuals caring for a family or community member with ADRD.
2.1.a.	Build capacity of community-based organizations to connect care partners with Alzheimer's and dementia resources.
2.1.b.	Create and maintain a publicly available, up-to-date database of care partner resources and service reviews.
2.1.c.	Educate families and care partners about the stages of dementia to facilitate utilization of timely, appropriate supports.
Objective 2.2	Improve and preserve financial well-being of care partners.
2.2.a.	Conduct a gap analysis of existing financial supports for care partners in Boston, with an emphasis on communities with sub-populations of African-American, Black, Hispanic, Latino/a/e/x and low-income, immigrant, and undocumented residents.
2.2.b.	Collaborate with partners to develop policies and programs to support care partners' financial well-being.
2.2.c.	Educate and help care partners navigate existing application processes for financial support.
2.2.d.	Build capacity among navigator organizations to assist care partners with applications to health insurance, determination of eligibility for a personal care attendant, and financial support services.
Objective 2.3	Increase the number of community-based supports for improving care partners' health, well-being, stress levels, and social connection.
2.3.a	Assess care partners' unmet needs through community-based listening sessions, anonymous surveys, and interviews with care partners.
2.3.b	Provide accessible, interactive programs to help care partners access respite care and learn techniques for stress reduction.
2.3.c.	Build the capacity of community and extended family members, volunteers, and community members to provide care partners with respite care.

Objective 2.4	Increase awareness among the general public about care partners' unique experiences, challenges, needs, and roles.
2.4.a.	Conduct an awareness campaign to educate Boston residents about the unique role care partners play in managing Alzheimer's and dementia.
2.4.b.	Provide training for primary care physicians on the demands of caregiving and the impact on care partners' physical and mental health.
2.4.c.	Train the direct care and social services provider workforce to support care partners in developing care plans, respite plans, crisis prevention, and crisis management.
Objective 2.5	Increase the number of care partners who complete routine preventive health exams for physical, dental, vision, and mental health.
2.5.a.	Partner with Aging Services Access Points to connect family care partners to existing supports and trainings related to caregiving skills, communicating with people living with Alzheimer's or a related dementia, and assisting with Activities of Daily Living.
2.5.b.	Develop trainings and tools and support medical providers in assessing whether patients are care partners and following up to encourage utilization of routine preventive care.
2.5.c.	Build capacity of health care navigators, social workers and other relevant support staff in the healthcare setting to assess and refer care partners seeking resources for people living with ADRD to caregiving and social services, including health insurance coverage, SNAP benefits, and other financial supports.

Success Measures:

- A range of providers report improved capacity to assess, support, and refer the needs of care partners
- Care partners report increased access to and improved quality of available supports
- Increase in awareness of community-based financial and legal supports
- Project collaborators report increased utilization of services by care partners
- Training and skills enhancement opportunities are available in multiple languages, in-person and virtually, and at varying dates, locations, and hours for care partners

Partners & Resources:

- BPHC Community Health Education Center
- Social workers, case managers, care coordinators, CHWs
- Direct care providers
- Medical care providers
- Faith-based organizations
- Community-based organizations
- Financial and legal services providers
- Alzheimer's Association
- Alzheimer's Association Community Resource Finder
- City of Boston Mayor's Health Line
- Employers
- Health insurers
- Public transit providers

PRIORITY 3: WORKFORCE SYSTEMS AND CAPACITY

GOAL: Boston's direct care and social services provider workforce has the capacity, competency, and incentives needed to meet the needs of people living with Alzheimer's disease or a related dementia and their care partners.

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Data Highlights

In BPHC's 2022 survey of social services providers, respondents cited key challenges:

- Understaffing/too few providers
- Insufficient compensation
- Too little training on how to work with older adults with ADRD
- Too little coordination and communication with other agencies
- Provider burnout
- Lack of workforce diversity

Care partners who joined BPHC's listening sessions need paid caregivers to have:

- Skills-based trainings in ADRD caregiving
- De-escalation training
- Training to provide culturally responsive and respectful care

"You definitely meet home care workers who are 80 years old and still delivering care. It's just their calling, but also they have a financial need to do so."

"Home care workers are often lauded as heroes but are not compensated as such."

The direct care workforce provides essential services for people living with ADRD – beyond care by medical professionals in clinical settings. In this strategic plan, the "paid caregiver workforce" encompasses frontline, direct care providers including *home health aides, personal care attendants*, and *adult day care center staff*, as well as social services providers who support clients through home visits, care partner support, and information and referrals, including social workers, case managers, and *community health workers.*

These providers are critical points of intervention for families, patients, and care partners, and are likely to have frequent, consistent, and extended contact with older adults with ADRD. However, in BPHC's survey of social service providers, respondents noted that the direct care sector is plagued by low pay, lack of effective training, and few professional development opportunities.

Both providers and care partners noted that the direct care provider workforce does not have enough capacity to meet the needs of Boston residents and highlight compensation and training as key needs.[23]

While social services providers pointed to specific gaps in their knowledge of how to work with older adults who have ADRD, frontline providers called for more training in how to work with older adults from different racial, ethnic, and cultural origins.

According to the Alzheimer's Association, "people living with Alzheimer's are nearly five times more likely to need skilled nursing facility care and three times more likely to require home health care as individuals without the condition."[24]Both the Alzheimer's Association and care partners BPHC interviewed affirm the need for home-based direct care providers who have dementia-specific knowledge, skills, and competencies. While certified nursing assistants and home health aides complete at least 75 hours of required training, Alzheimer's and dementia care is only one of 40 required topics covered.[22]

[23]*BPHC BOLD Dementia Assessment. Data Brief: Ability of the Social Service Sector in Boston to Meet the Needs of Older Adults. 2022.*
[24]*Alzheimer's Association. Dementia Training for Direct Care Workers Fact Sheet. (2023.) https://portal.alzimpact.org/media/serve/id/5d23ae7160dd4*

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Priority 3: Objectives and Strategies

Objective 3.1	Promote retention and advancement of the direct care provider workforce serving Boston residents with Alzheimer's disease or a related dementia
3.1.a.	Conduct a baseline assessment of existing wages, benefits, trainings, and wellness resources for direct care providers.
3.1.b.	Compile and disseminate best practices for compensation, benefits, trainings, and wellness resources for social services and direct care providers.
3.1.c.	Partner with direct care service providers' employers and labor unions to promote access to and utilization of existing wellness resources.
3.1.d.	Develop, implement, and promote existing and upgraded trainings for direct care providers based on current best practices in dementia caregiving.
Objective 3.2	Elevate and include direct care providers as critical components and engaged team members of a holistic clinical care team.
3.2.a.	Collaborate with direct care providers and care partners to promote existing care coordination models that elevate the role of paid caregivers.
3.2.b.	Pilot and expand novel care coordination models that elevate the role of the direct care provider in care teams for people living with ADRD.
3.2.c.	Compile existing best practices in dementia caregiving and collaborate with direct care providers and ensure compliance with best practices.
Objective 3.3	Advance policy, systems, and environmental approaches to improve direct caregiver workforce capacity and wellness.
3.3.a	Create a cross-sector advisory group with representation from direct care providers, health policy experts, and unpaid family care partners.
3.3.b	Generate and advance policy, systems, and environmental change recommendations for the paid caregiving workforce capacity and wellness.
3.3.c.	Support increased Medicare and Medicaid/MassHealth reimbursement rates and wage adjustments, informed by the local cost of living, for paid caregivers.
Objective 3.4	Promote age and dementia-competent workplaces.
3.4.a.	Develop a plan to make the City of Boston an age- and dementia-friendly employer
3.4.b.	Improve supports and benefits available to City of Boston employees who are family caregivers to an individual living with Alzheimer's disease or a related dementia.
3.4.c.	Provide ongoing age- and dementia-friendly training for public-facing City of Boston employees.

Success Measures:

- Increased availability of high-quality, direct care provider workforce training and skill building opportunities for dementia caregivers
- Number of direct care providers who complete trainings and report high learning and satisfaction
- Family and patient satisfaction with care coordination programs
- Adoption of city-level policies to support dementia caregivers
- Increased benefits for City of Boston employees who are caregivers

Partners & Resources:

- Age Strong Commission
- Alzheimer's Association
- City of Boston Mayor's Office
- BPHC Human Resources
- City of Boston Human Resources departments
- Medicaid/MassHealth
- SEIU 1199 United Healthcare Workers East
- Aging Services Access Points
- Direct care provider vendor agencies
- Institutions for continuing eduction
- Dementia caregiving research institutes

PRIORITY 4: RISK REDUCTION, EARLY DETECTION, AND DIAGNOSIS

GOAL:
Protect and promote brain health for all Boston residents throughout the lifespan.

Beyond age, genetics, and family-history, all of which are non-modifiable risk factors for ADRD, there are several health-related risk factors that evidence shows are modifiable. When addressed, these risk factors have a meaningful impact on one's risk of getting dementia (see list at left). Research suggests that addressing modifiable risk factors might prevent or delay up to 40% of dementia cases.

Some risk factors, such as excessive alcohol use and smoking, relate to individual health behaviors, while others, such as air pollution and education level, are shaped by structural and systemic forces. Risk factors like hearing loss, traumatic brain injury, physical inactivity, and chronic diseases including hypertension and diabetes are complex and influenced both by individual behaviors and social determinants of health.

Individuals often have a combination of dementia risk of factors but given that the brain changes that lead to dementia often begin years or decades before disease symptoms appear, there are opportunities to reduce dementia risk on a population level and intervene to slow the progression of disease.

According to data from the CDC, adults with subjective cognitive decline (SCD), an early indicator of possible future dementia, were more likely to report experiencing four or more risk factors for ADRD than were those without SCD (34.3% versus 13.1%). As of 2019, the nationwide prevalence of SCD was 11.3% overall, and increased from 3.9% among adults with no risk factors to 25.0% among those with four or more risk factors.[27]

ADRD Risk Factors

Non-Modifiable Risk Factors:

- Age
- Genetics
- Family History

Modifiable Risk Factors:

- Less education
- Hearing loss
- Traumatic brain injury
- Hypertension
- Obesity
- Diabetes
- Excessive alcohol use
- Smoking
- Social isolation
- Depression
- Physical inactivity
- Air pollution

In Boston, Black, Hispanic, and Latino/a/e/x residents have higher rates than White residents of hospitalization due to diabetes and hypertension.

Among Boston residents age 65+, Black adults are most likely to smoke and least likely to meet CDC physical activity guidelines.

[25]Livingston, Gill, et al. "Dementia prevention, intervention, and care: 2020 report of the Lancet Commission." The Lancet 396.10248 (2020): 413-446.
[26]Ibid.
[27]Omura JD, McGuire LC, Patel R, Baumgart M, Lamb R, Jeffers EM, Olivari BS, Croft JB, Thomas CW, Hacker K. Modifiable Risk Factors for Alzheimer Disease and Related Dementias Among Adults Aged ≥45 Years - United States, 2019. MMWR Morb Mortal Wkly Rep. 2022 May 20;71(20):680-685. doi: 10.15585/mmwr.mm7120a2.

It is possible to reduce the impact of ADRD, delay onset, or slow the progress of ADRD through screening and early diagnosis.[28] The first step in getting treatment to mitigate the effects of ADRD and to slow down cognitive decline is being diagnosed, however access to screening and diagnosis is not equally or equitably accessible. Black participants in Alzheimer's disease research studies were 35% less likely to be diagnosed with Alzheimer's and related dementias than white participants, despite national statistics that indicate that Black Americans are overall about twice as likely to develop dementias compared to whites.[29]

Given that family members are often the first to notice signs of decline and can help the individuals get screened, it is important to raise awareness within the entire community about ADRD and the critical dementia warning signs to know.[30]

Priority 4: Objectives and Strategies

Objective 4.1	Promote dementia screening among Boston residents at highest risk of ADRD.
4.1.a.	Increase primary care providers' knowledge of and competency with screening for and diagnosing dementia.
4.1.b.	Build linkages between medical providers and community-based organizations, faith-based organizations, and community health centers to facilitate dementia screening by qualified providers in community-based settings.
4.1.c.	Promote inclusion of dementia screening tools in electronic medical record and diagnostic databases.
4.1.d.	Expand the number of partnerships and collaborations between healthcare, social services, and community-based organizations working toward ADRD risk reduction and improved screening rates.
Objective 4.2	Promote awareness of brain health and ADRD risk reduction through culturally and linguistically accessible public health communications.
4.2.a.	Implement culturally and linguistically tailored public health communications campaigns that promote awareness of evidence-based strategies, services, and supports for reducing ADRD risk.
4.2.b.	Deliver community-based education about brain health, chronic disease risk factors, and ADRD risk reduction in partnership with community- and faith-based partners.
4.2.c.	Host interactive, community-based events to promote lifestyle changes and behaviors that reduce chronic disease and ADRD risk.
Objective 4.3	Increase collaboration between brain health, chronic disease programs, and stakeholders advancing brain health across the life course.
4.3.a	Convene a working group of disease-specific organizations to improve coordination and integrate culturally and linguistically responsive brain health messaging into existing disease prevention campaigns.
4.3.b	Convene partners in the housing, built environment, education, and health care access sectors to ensure residents in need of support with social determinants of health have access to culturally and linguistically responsive dementia and brain health information.

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[28]Ibid.
[29]Lennon, et al. Black and white individuals differ in dementia prevalence, risk factors, and symptomatic presentation. Alzheimer's and Dementia.2021; https://doi.org/10.1002/alz.12509
[30]HRiA, BPHC. BOLD Needs Assessment. Data Brief: Prevalence of Alzheimer's/Dementia and Related Risk Factors among Boston Residents. 2022.

4.3.c.	Partner with City of Boston agencies, initiatives, and school systems that provide direct brain health, injury prevention, and chronic disease prevention services to integrate brain health and dementia topics into programming and communications.
Objective 4.4	Elevate ADRD risk reduction efforts in policy and advocacy work.
4.4.a.	Assess the landscape of ADRD policy in Massachusetts and nationwide related to ADRD risk reduction, screening, and diagnosis.
4.4.b.	Provide tools and technical assistance to partners' Intergovernmental Relations Offices to build capacity for education and advocacy related to ADRD and brain health.
4.4.c.	Embed ADRD risk reduction, screening, and diagnosis into policy and planning initiatives within BPHC and among other City of Boston agencies.
4.4.d.	Provide ongoing education among city- and state-level policymakers about ADRD, chronic disease risk factors and the impact of social determinants on brain health.

Success Measures:

- Dementia screenings increase over baseline among African American, Black, Hispanic, and Latino/a/e/x Boston residents
- Increase in number of clinical and community-based providers offering dementia screening in Boston
- Multi-channel, multi-lingual, culturally responsive messaging campaigns implemented that integrate brain health and chronic disease prevention topics
- Increase in number of city- and state-level policy makers who are aware of and show support for policy proposals advancing ADRD risk reduction and screening

Partners & Resources:

- City of Boston Chronic Disease Prevention and Control Program
- Age Strong Commission
- Dementia Friendly Massachusetts
- Alzheimer's Association of Massachusetts and New Hampshire
- Boston City Councilors
- Community health centers
- Primary care providers, geriatricians, neurologists
- Boards of registration for nurse practitioners, physician assistants, and medicine
- Community- and faith-based organizations

PRIORITY 5: SURVEILLANCE DATA COLLECTION

GOAL: Boston has sustainable data collection systems for ongoing needs assessment related to ADRD and the experiences of people living with ADRD and their care partners.

The Boston BOLD Needs Assessment identified a key gap in the City of Boston's Alzheimer's, dementia, and caregiving data collection efforts. While available data show that ADRD disparities and inequities playing out at the national level are also happening here in Boston, there is not yet true prevalence data quantifying the number of people in Boston who have dementia and disaggregating those data by neighborhood, race, ethnicity, and socioeconomic identifiers. Furthermore, the city has not yet implemented data collection systems to measure the burden and impact of ADRD caregiving on Boston residents.

BPHC will work to sustain quantitative and qualitative data collection efforts initiated through the BOLD needs assessment, including compiling, analyzing, and reporting out on hospitalizations and mortality due to ADRD, and explore methods for establishing ADRD prevalence

in Boston using the All-Payer Claims Database. Critically, BPHC will also incorporate questions about ADRD caregiving from the CDC-developed **BRFSS Caregiving Module** into the Boston Behavioral Risk Factor Surveillance System.

Priority 5: Objectives and Strategies

Objective 5.1	Promote ongoing collection of population-level surveillance data on dementia prevalence and caregiving.
5.1.a.	Incorporate questions from the CDC's Caregiving Module into the Boston BRFSS.
5.1.b.	Conduct callback surveys with Boston BRFSS respondents who self-identify as caregivers.
5.1.c.	Establish a standard data collection procedure for tracking surveillance data related to ADRD hospitalization, mortality, and related risk factors.
Objective 5.2	Establish estimated baseline measures for dementia screening among Boston residents.
5.2.a.	Pilot data collection methodologies in partnership with safety net hospitals and community health centers, with an emphasis on clinical facilities that serve low-income, immigrant, African American, Black, Hispanic, and Latino/a/e/x residents.
5.2.b.	Utilize baseline screening rates to inform the development of culturally and linguistically tailored dementia screening approaches for high-risk populations.
5.2.c.	Promote the use of baseline screening measures in the design of workforce capacity building efforts for medical providers.
Objective 5.3	Promote policy and systems change related to ADRD data collection.
5.3.a	Develop and disseminate data briefs and infographics to the public, the ADRD workforce, and city- and state-level policy makers.
5.3.b	Identify opportunities to highlight ADRD data in existing research and data collection initiatives such as the Health of Boston Report and the Boston Community Health Needs Assessment.
5.3.c.	Conduct an analysis of policy and systems levers to enforce standardized ADRD surveillance data collection.
5.3.d.	Establish an ADRD policy and systems working group with participants who have expertise in the collection, analysis, and application of surveillance data.

Success Measures:

- Questions from the CDC's BRFSS Cognitive Decline and/or Caregiving Modules are routinely included in the BBRFSS
- Partners establish baseline dementia screening rates for Boston residents, and specific rates for African American, Black, Hispanic, and Latino/a/e/x residents
- Baseline dementia screening rates inform workforce capacity building initiatives among medical and clinical health providers and the design of community-clinical linkages

Partners & Resources:

- BPHC Science, Technology, and Innovation Office
- MA Center for Health Information and Analysis
- All Payer Claims Database
- MA Department of Public Health
- Boston Medical Center
- Alzheimer's Association
- Community health centers
- Boston BRFSS
- Center for Medicare and Medicaid Services Mapping Medicare Disparities Tool

NEXT STEPS

BPHC was approved for funding to continue the Boston BOLD Project through the CDC's "BOLD Public Health Programs to Address Alzheimer's Disease and Related Dementias" initiative (CDC-RFA-DP-23-0010). The next phase of the Boston BOLD Project begins in September of 2023. Key priorities in project Year 1 will be growing the BOLD Advisory Committee into a Stakeholder Coalition, expanding upon the strategies and objectives outlined here to create a detailed ADRD implementation plan, and in subsequent years, putting the plan into action.

BPHC will establish a working group for each strategic plan priority, envisioned as a multi-disciplinary collaborative of providers and practitioners with knowledge of brain health topics and public health interventions at each level of ADRD prevention. Critically, BPHC will form an equity in implementation working group to ensure that health equity is embedded in all that we do together to enact the strategic plan.

Working group members will collaboratively develop an implementation plan, including recommendations for reviewing, updating, and sustaining ADRD priorities beyond the duration of funding. BPHC will identify implementation leads to move priorities forward, and utilize a template developed by Health Resources in Action (see Appendix E), as well as the Commonwealth of Massachusetts' ADRD State Plan and the Healthy Brain Initiative Road Map, to shape Boston's implementation plan.

BPHC will facilitate a regular review and update cycle with the aim of publishing an updated strategic plan every three years. In partnership with the BOLD Stakeholder Coalition, BPHC will begin a review of successes and address challenges and gaps approximately one year before each plan expires. Reviewers and planners will re-assess priorities and activities, with an eye toward those that are most sustainable, highest-impact, and aligned with other relevant efforts.

BPHC welcomes input and collaboration from stakeholders across sectors with direct experience or interest in better serving the residents of Boston who are living with or at highest risk of developing ADRD. To get involved, or for more information about BPHC's brain health, Alzheimer's and dementia work, please contact BOLD@bphc.org.

BOLD Project Team Contact Information:

Eugene Barros, Boston BOLD Project Director

Division Director, Healthy Homes and Community Supports Division

Boston Public Health Commission

ebarros@bphc.org

Andrea Dettorre, Boston BOLD Project Director

Senior Program Director, Healthy Homes and Community Supports Division

Boston Public Health Commission

adettorre@bphc.org

APPENDIX A: KEY TERMS AND ACRONYMS

Term	Definition/Description
Priority	Key issues identified from an assessment that provide a focus for planning.
Goal	A goal is a broadly stated, non-measurable change in the priority area. It describes in broad terms a desired outcome of the planning initiative.
Objective	Objectives articulate goal-related outcomes in specific and measurable terms. Objectives state how much of what you hope to accomplish and by when. Ideally, objectives are SMART (Specific, Measurable, Achievable, Relevant, Time-phased).
Success Measures	Measure(s) of progress or completion of a goal or objective. These measures demonstrate if the goal or objective was successful in impacting the priority.
Strategies	A strategy is a statement of HOW an objective will be achieved. It is less specific than action steps but tries broadly to answer the question, "How can we get from where we are now to where we want to be?"
Caregiver	Anyone who delivers medical care or social supports to people living with ADRD and their care partners
Care Partner	An individual who provides unpaid care for or supports people who are living with ADRD

ADRD   Alzheimer's Disease and Related Dementias

BOLD   Building Our Largest Dementia Infrastructure for Alzheimer's Act

BPHC   Boston Public Health Commission

BRFSS   Behavioral Risk Factor Surveillance System

CDC   Centers for Disease Control and Prevention

HBI   Healthy Brain Initiative

HRiA   Health Resources in Action

APPENDIX B: COMMUNITY NEEDS ASSESSMENT CONTRIBUTORS

Stakeholder	Sector
1199 SEIU United Healthcare Workers East	Labor Union
Alzheimer's Association, MA and NH Chapter*	Research + Advocacy
The Black Ministerial Alliance of Greater Boston/TenPoint Coalition*	Faith-Based Organization
Boston Housing Authority*	Public Housing
Boston Medical Center Geriatrics Section*	Hospital
Boston Senior Home Care	Aging Services Access Point
Center for Alzheimer's Research and Treatment at Brigham and Women's Hospital	Research + Advocacy
Central Boston Elder Services	Aging Services Access Point
City of Boston Age Strong Commission*	Area Agency on Aging
ETHOS	Aging Services Access Point
Fenway Health	LGBTQIA+ Health Provider
Greater Boston Chinese Golden Age Center	Social Services Organization
Jewish Family and Children's Services	Social Services Organization
La Alianza Hispania	Social Services Organization
Massachusetts Executive Office of Elder Affairs	State Agency
Multicultural Alzheimer's Prevention Program at Massachusetts General Hospital*	Research + Advocacy
Upham's Corner Health Center	Community Health Center

*BOLD Advisory Committee Member

APPENDIX C: STRATEGIC PLANNING PARTNERS

BPHC acknowledges the following partners in the development, review, and implementation of the Boston ADRD Strategic Plan:

Priority Area 1: Finding and Connecting to Support Services

Sandy Auerbach, MD	Boston Medical Center / Boston University Chobanian & Avedisian School of Medicine
Megan Cheung	Greater Boston Chinese Golden Center
Margery Gann	ETHOS (Aging Services Access Point)
Pamela MacLeod	Executive Office of Elder Affairs
Nicole McGurin	Alzheimer's Association of Massachusetts and New Hampshire
Andrea Patton	Boston Commission for Persons with Disabilities
Emily Shea	Age Strong Commission
Beth Soltzberg	Jewish Family and Children's Services

Priority Area 2: Caregiver Support

Marisol Amaya	La Alianza Hispana
Leon Bethune	Boston Public Health Commission
Andrea Burns	Age Strong Commission
Susan Ciccariello	LTSS Continuum and Institutional Programs, Commonwealth of MA
Alicia Gomez	Boston Senior Home Care
Jill Hovanasian	Alzheimer's Association of Massachusetts and New Hampshire
Bob Linscott	Age Strong Commission
Lisa Mitchell, RN	Family Caregiver-Advocate
Johnna Murphy	Boston Public Health Commission
Jessica Roque	Jewish Family & Children's Services

APPENDIX C: STRATEGIC PLANNING PARTNERS CONT.

Priority Area 3: Workforce/System Capacity

Dora Camara	1199 SEIU United Healthcare Workers East
Michele Clark	Boston Public Health Commission
James Fuccione	MA Healthy Aging Collaborative
John Kane	Boston Housing Authority
PJ McCann	Boston Public Health Commission
Linnea Rego	1199 SEIU United Healthcare Workers East
Bonnie-May Shantz	Executive Office of Elder Affairs
Lainey Titus Samant	Alzheimer's Association of Massachusetts and New Hampshire

Priority Area 4: Risk Reduction, Early Detection, and Diagnosis

Sonia Carter	Boston Public Health Commission, Chronic Diseases Division
Hollis Day, MD	Boston Medical Center / Boston University Chobanian & Avedisian School of Medicine
Chelsea Gordon	Alzheimer's Association of Massachusetts and New Hampshire
Michael Kincade	Center for Alzheimer's Research and Treatment & Massachusetts Alzheimer's Disease Research Center
Christine Ritchie, MD	MA Alzheimer's Disease Research Center
Corinne White	Age Strong Commission

APPENDIX D: BOSTON BOLD CITYWIDE ADVISORY COMMITTEE 2021 - 2023

Boston Public Health Commission
Public Health Dept. for the City of Boston

Boston Medical Center
Section of Geriatrics

City of Boston Age Strong Commission
Boston Area Agency on Aging

Boston Senior Home Care
Aging Services Access Point

Alzheimer's Association Massachusetts and New Hampshire Chapter

Multicultural Alzheimer's Prevention Program at MGH

Black Ministerial Alliance/Ten Point Coalition

Inquilinos Boricuas en Acción

Boston Housing Authority

City of Boston Mayor's Commission for Persons with Disabilities

APPENDIX E: IMPLEMENTATION PLANNING TEMPLATE

Priority 1:					
Goal 1:					
Objective 1.1:					
Success Measures (can be at the goal level or by objective, depending on the measurability of the objectives) 1. 2.					
Strategies	**Actions**	**Person(s) Responsible** L=Lead, M=Manage, I=Implement	**Timeline**		
			Y1	**Y2**	**Y3**
Resources Required (human, partnerships, financial, infrastructure or other) •					
Monitoring/Evaluation Approaches •					
Objective 1.2					
Success Measures 1. 2.					
Strategies	**Actions**	**Person(s) Responsible** L=Lead, M=Manage, I=Implement	**Timeline**		
			Y1	**Y2**	**Y3**
Resources Required (human, partnerships, financial, infrastructure or other) •					
Monitoring/Evaluation Approaches •					
Objective 1.3					
Success Measures 1. 2.					
Strategies	**Actions**	**Person(s) Responsible** L=Lead, M=Manage, I=Implement	**Timeline**		
			Y1	**Y2**	**Y3**
Resources Required (human, partnerships, financial, infrastructure or other) •					
Monitoring/Evaluation Approaches •					