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BPHC BOLD Dementia Assessment

Data Brief: Experience and Needs of Unpaid
Caregivers to Persons Living with Dementia in Boston

Submitted to:

Boston Public Health Commission
Division of Healthy Homes and Community Supports
1010 Massachusetts Ave, Boston, MA 02118



Health Resources in Action
Advancing Public Health and Medical Research

Introduction & Background

The BOLD Community Needs Assessment was undertaken by the Boston Public Health Commission (BPHC) in partnership with Health Resources in Action and other community partners, with funding from the CDC. The aim was to assess the needs of residents related to memory loss, Alzheimer's disease and related dementias and inform future planning efforts.

The BOLD assessment team conducted a series of 16 key informant interviews with a broad range of Boston-based stakeholders working with older adults, and two listening sessions with unpaid caregivers to assess their experiences, access to programs and supports, and needs and recommendations to improve the services available to those living with Alzheimer's disease and related dementias (ADRD) and their caregivers. This data brief presents the results from this qualitative data collection as well as available secondary data as it relates to the caregiver experience.

Data suggest that in the US, 83% of the help provided to older adults currently comes from unpaid caregivers, namely family members or friends. And nearly half of caregivers in the US are caring for someone with Alzheimer's or another form of dementia¹. Such informal caregiving scenarios take place often because of a desire to keep the person living at home, the caregiver's proximity to the person needing care, or the caregiver's perceived obligation to the person needing care. The care provided to people with Alzheimer's or other dementia can be extensive, including helping with self-care and mobility, monitoring medication and treatment adherence, managing behavioral symptoms, finding and managing healthcare and support services, managing other health conditions, providing emotional support and sense of security, etc. The experience of caregiving places tremendous burden and stress on the caregiver, putting them at higher risk for depression or other mental health disorders, greater physical and emotional strain, and increased susceptibility to disease and health complications for themselves. Disparities by race/ethnicity are evident among caregivers as well. In the US, Hispanic, Black and Asian American caregivers to individuals with dementia appear to experience greater care demands, receive less outside help/formal service use, and are more likely to have depression compared with white caregivers.

Prevalence of Caregiving Responsibility in Boston

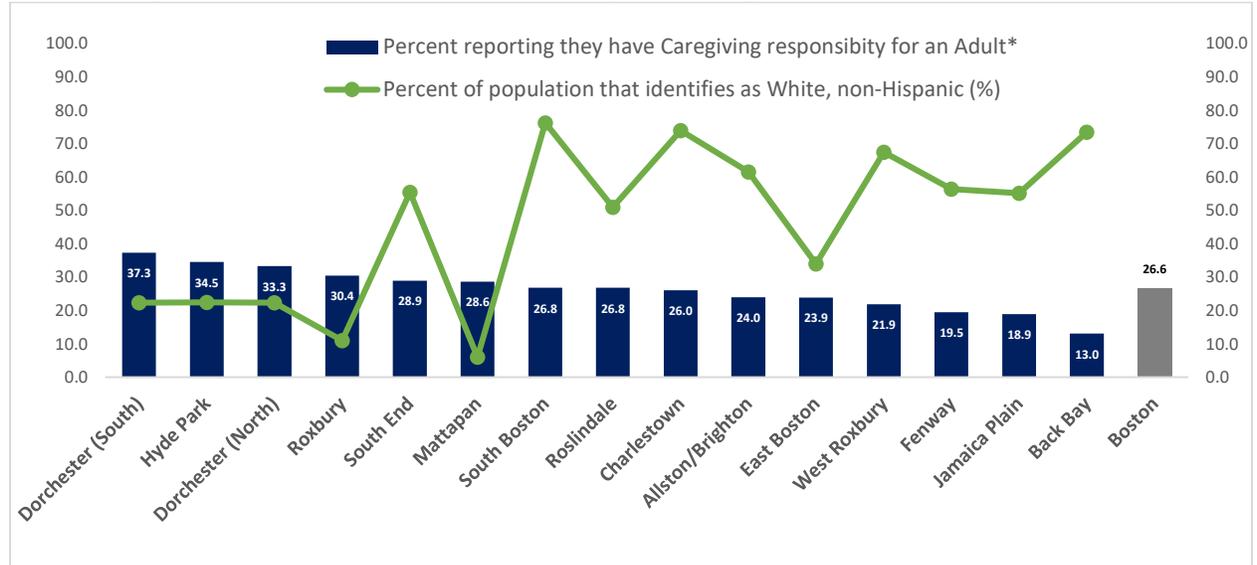
Data from the Behavioral Risk Factor Surveillance Survey (BRFSS) provides some insight into the prevalence of caregiving responsibilities among Boston residents. The percentage of Boston residents who reported that they have caregiving responsibility for an adult are illustrated in **Figure 1**. Data have been stratified by neighborhood and overlaid with the percentage of the population that identified as white, non-Hispanic.

Overall, about 27% of Boston residents self-reported caregiving responsibilities for an adult. These data further showed that the percentage was highest in the neighborhoods of Dorchester (37% and 33% for South and North respectively), Hyde Park (34%), and Roxbury (30%) and lowest in the neighborhoods of Fenway (19%), Jamaica Plain (19%), and Back Bay (13%). The figure additionally illustrates that the prevalence of caregiving aligns with the racial/ethnic diversity of the population. Specifically, those neighborhoods with a higher percentage of caregivers (Dorchester, Hyde Park, and Roxbury) generally have lower percentages of the population that identify as white, non-Hispanic (range 11% to 22%)

¹ Alzheimer's Association. 2022 Alzheimer's Disease Facts and Figures. Alzheimers Dement 2022;18.

compared to those neighborhoods with lower percentages of caregivers (Fenway, Jamaica Plain, Back Bay) which are more likely to have higher percentages of the population that identify as white, non-Hispanic (range 55% to 73%).

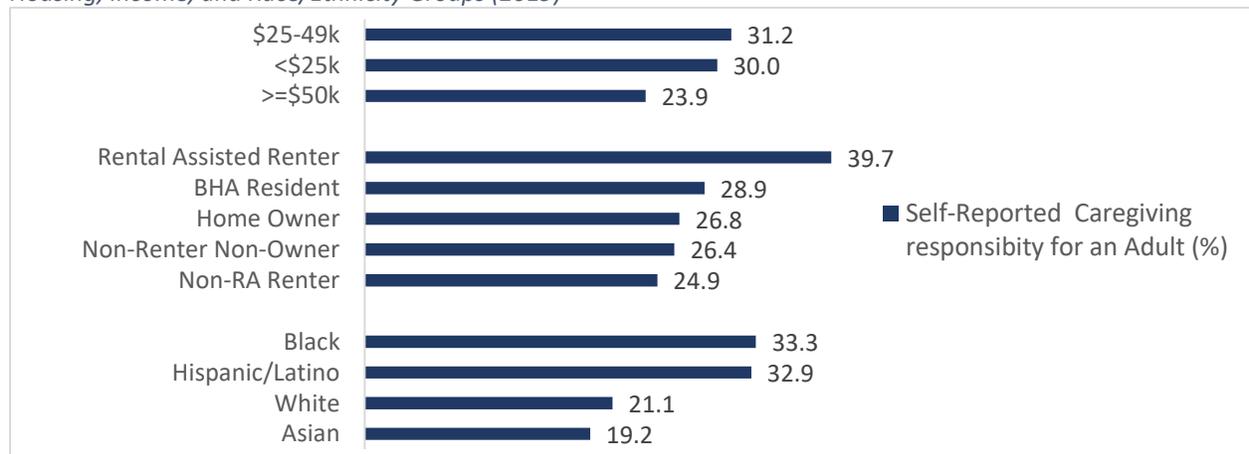
Figure 1. Percent of Boston Residents (all adults) that Self-reported Caregiving Responsibility for an Adult (2019) and Percent of Population that is White, non-Hispanic, by Boston Neighborhood (2019)



Data Source: Self-report data - Boston Behavioral Risk Factor Surveillance System, Boston Public Health Commission, data reflect 2019; Note: data reflect responses among all Boston adults; Demographic data - U.S. Census Bureau, American Community Survey, BPDA Research Division Analysis (2015-2019)

When data were stratified by sub-group, some additional differences were observed (Figure 2). Percentages of self-reported caregiving were higher among low-income households (31%), rental assisted renters (40%), Black adults (33%), and Hispanic/Latino adults (33%).

Figure 2. Percent of Boston Residents (all adults) that Self-reported Caregiving Responsibility for an Adult, by Housing, Income, and Race/Ethnicity Groups (2019)



Data Source: Self-report data - Boston Behavioral Risk Factor Surveillance System, Boston Public Health Commission, data reflect 2019; Note: data reflect responses among all Boston adults

The BRFSS data also provides estimates for the percentage of Boston adults who have a functional disability, including memory decline and difficulties with mobility or doing errands independently. While

not an exhaustive list of the physical and cognitive disabilities experienced by Boston residents, these data provide some insight into the populations of adults who may be in greater need of support around daily activities and who are likely to be recipients of unpaid caregiving support.

Table 1 summarizes the findings for the three disability questions that are included in the BRFSS for Boston residents. Percentages are reported for all adults and for adults aged 65 years and older; however, stratifications and sub-group analyses were limited due to small sample size in the latter.

Overall, for each disability type, percentages are generally higher among Black and Hispanic adults, BHA residents, rental assisted renters, and low-income households. Particularly striking findings pertain to those adults living in BHA housing, which may relate to the conditions and situations that make an individual eligible for such housing to begin with:

- 35% BHA residents self-reported difficulty concentrating, remembering, or making decisions
- 24% BHA residents self-reported difficulty doing errands alone, such as visiting a doctor or shopping
- 36% of BHA residents self-reported serious difficulty walking or climbing stairs

Table 1. Percent of Boston Residents (all adults) that Self-reported a Disability, by Type (2019)

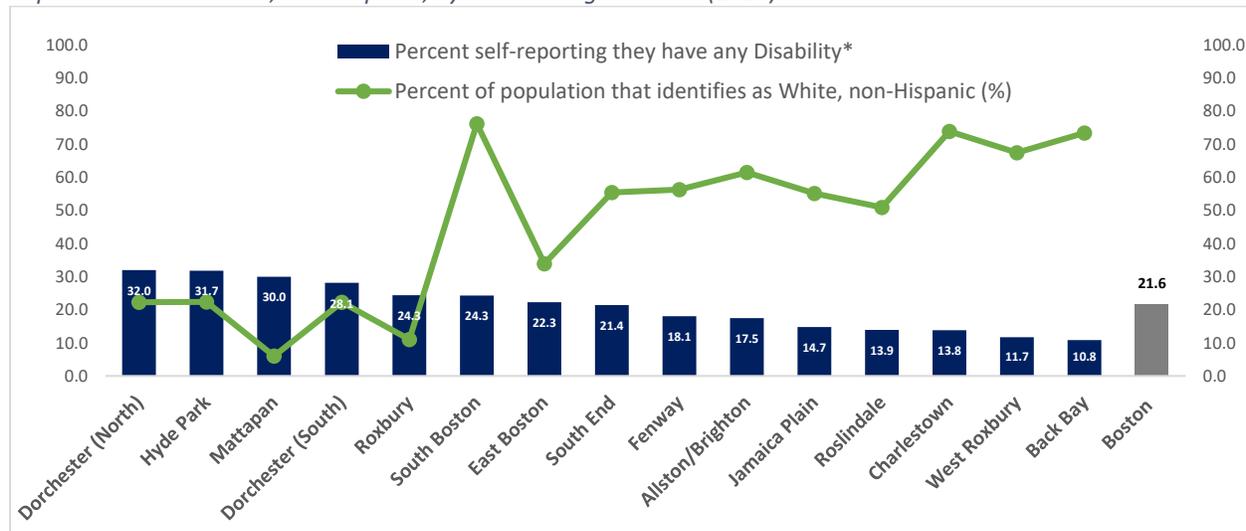
<i>Disability Type</i>	<i>% All Adults</i>	<i>Sub-Group Differences</i>	<i>% Adults aged 65+</i>	<i>Sub-Group Differences</i>
Difficulty concentrating, remembering, or making decisions, 2019	13%	Higher among Black adults (14%) Higher among Hispanic adults (20%) Higher among BHA residents (35%) Higher among Rental assisted (27%) Higher among low-income (23%) Higher among LGBTQ+ (20%)	12%	Higher among low-income households (21%)**
Difficulty doing errands alone, such as visiting a doctor's office or shopping	8%	Higher among Black adults (11%) Higher among Hispanic adults (13%) Higher among BHA residents (24%) Higher among rental assisted (20%) Higher among low-income (17%)	14%	Higher among low-income households (23%)**
Serious difficulty walking or climbing stairs	11%	Higher among Black adults (19%) Higher among Hispanic adults (16%) Higher among BHA residents (36%) Higher among rental assisted (31%) Higher among low-income (27%)	30%	Higher among low-income households (46%)**
Any of the above disabilities*	22%	see Figures 3 and 4 below	37%	Higher among low-income households (51%)**

*Note: Neighborhood stratification are not reported for specific disabilities due to small sample size; *Any of the Above includes any of: difficulty doing errands independently, difficulty walking or climbing stairs, difficulty concentrating or remembering; **stratifications other than by income were suppressed due to small sample size among 65+ age group in many categories*

The aggregated variable of ‘any disability’ allowed for more in-depth analyses and stratification. As illustrated in **Figure 3**, the percentages of all adults who self-reported any of the three functional disability types were highest in the neighborhoods of Dorchester (32% and 28%, North and South respectively), Hyde Park (32%), and Mattapan (30%) and lowest in the neighborhoods of West Roxbury (12%) and Back Bay (11%). Overlaid with the percentage of the population that identified as white, non-Hispanic, a clear pattern can be observed. Those neighborhoods with the higher percentages of adults with a functional disability (Dorchester, Hyde Park, and Mattapan) have markedly lower percentages of the population that identify as white, non-Hispanic (range 6% to 22%) compared to those

neighborhoods with lower percentages of adults with a functional disability (West Roxbury and Back Bay) which have some of the highest percentages of the population that identify as white, non-Hispanic (67% and 73%, respectively).

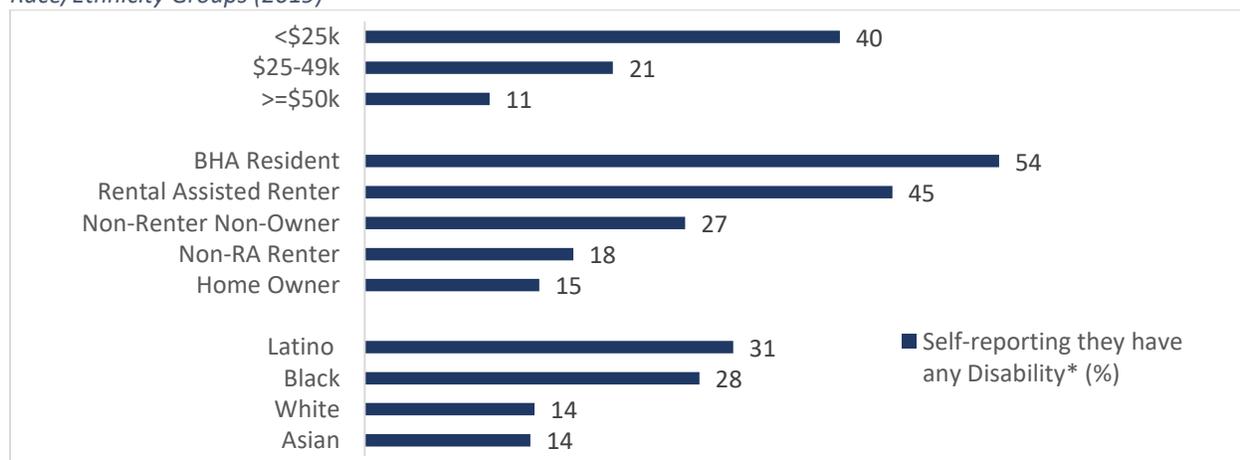
Figure 3. Percent of Boston Residents (all adults) that Self-reported Having any Disability (2019) and Percent of Population that is White, non-Hispanic, by Boston Neighborhood (2019)



Data Source: Self-report data - Boston Behavioral Risk Factor Surveillance System, Boston Public Health Commission, data reflect 2019, Note: data reflect responses among all Boston adults; Demographic data - U.S. Census Bureau, American Community Survey, BPDA Research Division Analysis (2015-2019); Note: hospitalization rates shown are age-adjusted; *Any disability includes any of: difficulty doing errands independently, difficulty walking or climbing stairs, difficulty concentrating or remembering

Additional sub-group analyses showed the percentages of adults with any type of functional disability to be highest among low-income households (40%), BHA residents (54%), rental assisted renters (45%), Hispanic/Latino adults (31%), and Black adults (28%) (Figure 4).

Figure 4. Percent of Boston Residents (all adults) that Self-reported Having any Disability, by Housing, Income, and Race/Ethnicity Groups (2019)



Data Source: Self-report data - Boston Behavioral Risk Factor Surveillance System, Boston Public Health Commission, data reflect 2019; Note: data reflect responses among all Boston adults; *Any disability includes any of: difficulty doing errands independently, difficulty walking or climbing stairs, difficulty concentrating or remembering

Challenges Faced by Unpaid Caregivers

Many adults, often aging adults themselves, are faced with the responsibility of caring for a loved one with cognitive decline. Key informant interview and focus group participants discussed some of the challenges they faced when caring for their spouses, parents, grandparents, and other family members.

Early diagnosis

The first step in getting treatment to mitigate the effects of AD/DRD and to slow down cognitive decline is being diagnosed. However, most caregivers indicated that many years elapsed from the time they first noticed symptoms of cognitive decline in a loved one to obtaining a diagnosis from a healthcare provider. Several issues emerged from discussions with residents as barriers to obtaining an earlier diagnosis.

As noted in the Needs of Older Adults data brief, *normalization of memory loss in older age* is a major barrier to early diagnosis. Because family members are often the ones to notice the first signs of decline and can help the person get screened, it is critical to raise awareness about Alzheimer's disease and related dementias and the critical warning signs to be aware of. This should be undertaken with a focus on the entire community, not just older adults, and including primary care providers (PCPs). Education related to the importance of screening and early diagnosis should emphasize the options to slow down cognitive decline. Otherwise, the motivation to urge a loved one to get a diagnosis is dampened by the belief that Alzheimer's/dementia is a "death sentence" with no available treatment options.

Stigma

The second theme that emerged from discussions was the *stigma* surrounding any type of mental health disorders. Caregivers mentioned difficulties in broaching the subject to their loved ones for fear of offending them and their sense of pride, particularly in the early stages of the disease. They noted that discussing memory loss can be offensive to someone used to being independent.

"My dad has dementia. You don't understand it until you experience it. He used to be involved in the community a lot. Always wanted to stay educated and informed. Maybe 6 years ago, he couldn't remember anything. He would come visit me and repeat all of the stories. Started to realize that something was not right, but he didn't say anything – he lives alone." – Focus Group participant

Awareness of available help

The third theme was *lack of knowledge about where to seek help* for a relative when suspecting that something is wrong. For some, the first place to seek information was the internet and internet support groups. The second place, for those who had health insurance, was their PCP. They mentioned that information about where to seek diagnoses was not readily available and PCPs did not always offer screenings. After diagnosis, participants noted being unprepared and unaware of where to obtain support.

Cultural humility

When bringing up issues related to personality change with a PCP or specialist, multiple caregivers mentioned being offended by having their loved ones referred to a psychiatrist, underscoring the need for cultural humility training among providers. As an aging Black caregiver described when her husband's provider referred him to a psychiatrist, ***"I thought, 'is he crazy?' I don't know. He never went to see the psychiatrist; it made me think that he's crazy."***

There are disparate views about the obligations perceived by caregivers of diverse racial/ethnic backgrounds. Some interviewees noted that caregivers from cultures where caring for aging adults is

seen as a duty of family members, such as in African and Caribbean communities, may be reluctant to access support services and accept outside help. Others, however, indicated that it was a problem of access, not of desire to get help.

Most participants noted that there were insufficient support services to meet the needs of Boston's diverse population. As one interviewee noted, ***"It doesn't do anybody any good to tell people about support groups if there is no support group in their native language."***

Emotional distress

Caretaking for a loved one with ADRD causes a lot of emotional distress in the family. Participants mentioned being upset by their loved ones not recognizing them and by observing changes in personality. One focus group participant described her experiences interacting with her grandmother who is living with dementia: ***"Sometimes she does not remember who we are, sometimes she almost remembers. That gives us hope that she still has those memories of who we are. It is hard when your family member thinks you are a stranger."***

As a social services provider working with Latino residents summed up, ***"It is hard for caregivers because their family member's personality is changing. People don't understand why their mother or father doesn't recognize them or is saying, 'I hate you.'"***

Participants noted that the stress can give rise to a lot of conflicts in the family. As one social service provider described, ***"Behavioral symptoms may cause conflict in the family because relatives do not understand what is causing behavior."***

Post diagnosis support and care coordination

Over and over, we heard from caregivers that a *support structure* following diagnosis was lacking. Caregivers indicated not knowing what to do or where to obtain help when their family member finally received a diagnosis. Caregivers reported that navigating the health care system was complicated and stressful, but necessary.

They mentioned having follow-up visits that they needed to coordinate, which are time-consuming and confusing, particularly for non-native English speakers. Some caregivers noted that they did not fully understand the diagnosis and were unsure about the next steps to take. Caregivers did not feel that providers took the time to fully explain their loved one's diagnosis and its implications. As key supports for medication adherence, some indicated they were unsure about what medications their relative needed to take, and what each one was for.

Others were not offered referrals to or information on available social services. Overall, caregivers indicated that their best support and primary source of information were other caregivers. Further, some of the supports that caregivers were offered or received were not useful. One person sought a nurse to help her take care of her ailing husband; instead, she was offered cooking and cleaning help, which she did not need.

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

- Focus group participant

Another participant described her experience with a social worker, ***"I feel like the social worker wasn't trained well. She asked things like, 'do you have food at home', but did not ask many questions specific to the diagnosis."*** She continued explaining that the after-visit summary, ***"wasn't very extensive, and it was just so generic."***

Cost and insurance issues

Caregivers faced numerous cost and insurance-related barriers to obtaining the support they needed. First, caregivers noted that taking care of a person with ADRD was a “full-time job.” Many mentioned that they had difficulty maintaining a day-job while caretaking, which placed a lot of stress on them.

Transportation

Boston has a good public transportation system, that includes reduced or free ride options for older adults. In addition, some agencies, CBOs, and insurance companies pay for transportation to care. Despite this, transportation was often mentioned as a barrier for their loved one to receive care.

Some participants mentioned using a private car, but those without a car said that arranging for transportation was difficult and/or costly. For one, free transportation is not available for the caregiver, only the patient, or the transportation must be requested 24 hours in advance. Second, it may take a long time for the transportation service to pick up the client. Third, drivers are not trained to deal with older adults, particularly those with cognitive issues. Because many services are far away from where residents live, it can be very time consuming.

In trying to arrange travel to a day care center for a relative with dementia, a focus group participant illustrated the barriers, *“My aunt has a little difficulty walking and I’m not sure what would happen when she got off the shuttle and we just haven’t worked it out. When she starts initially it will be family [taking her] and then we will try to figure out the travel for her.”*

As a social services provider explained, *“Most insurance companies will pay for transportation to adult day care but will not pay for a companion or a family member who travels with the client to go home. The companion is expected to wait 6-7 hours while the relative is in day care.”*

Multiple forms of discrimination were also described when trying to arrange transportation for someone with a disability, including drivers being rude, particularly if the person does not speak English well or has an accent, and saying that they don’t have room in the van. A social services provider working with Asian and Latino residents noted requesting public, specialized transportation is *“a very tedious process”* and indicted that language was a barrier.

Unmet needs of unpaid caregivers

Several unmet needs emerged from discussions with residents and are illustrated in some of the challenges described above.

Hands on support

Caregivers need more tangible supports to meet their caregiving needs. Caregivers need access to respite care, particularly nurse aides to stay overnight given that people with ADRD at some stages need to be constantly cared for. They also need easily accessible, local, quality, day care centers where their relatives can spend the day and receive stimulation to prevent cognitive decline. Residents emphasized that day care centers should be distributed throughout the city, so they don’t have to travel long distances to take their relatives to day care. Also, staff at day care centers should be trained to prevent people from exiting the center unsupervised.

As noted by several respondents, peer support groups are a good source of information and are helpful to mental health but are not enough. As one aging caregiver noted, *“I am in a support group that meets every Tuesday night, I get to learn from other people in the support group, get a lot of emails about classes and other resources, but cannot always get there... I really want to know the best way to handle my situation [husband with dementia]. This is something we are not prepared for, it just comes.”*

Another caregiver expressed the same, *“I noticed [programs offered are] primarily info sessions, emails asking her to join Zoom meetings and learn more about dementia, but no resources on how to handle her individual situation.”* She notes that while helpful to prepare for what to expect in the future, these sessions do not offer hands on support.

A caregiver explained that a social worker offered help cooking and cleaning, which she didn't need, and reflected, *“Maybe I should have said, ‘yes,’ because then I would have somebody, but now they closed my case.”*

Transportation

As noted above, taking their relatives to health services is a problem for many caregivers. Many caregivers rely on public transportation services. Thus, providing more free or low-cost transportation services that take into consideration the needs of caregivers and simplifying the process to request these services is a priority area.

Care coordination support

Navigating the insurance and healthcare landscape is very difficult to caregivers, including those who are aging themselves and who are second language English speakers. Case managers who can explain what services are available for free or at low-cost, who can help with setting up appointments and arranging transportation to services, and who can provide guidance on insurance issues and help with paperwork are needed. Given the diversity of Boston residents, more case managers who speak multiple languages and can provide culturally competent services are needed.

Pre-and post-diagnosis support systems

The period leading up to a diagnosis and immediately following the diagnosis is extremely stressful and confusing for clients and family members. Caregivers would benefit from being assigned a case manager as soon as their relative exhibits signs of cognitive decline. Information about available services and supports should be written in clear language, available in multiple languages, and disseminated broadly using different methods (internet, radio, printed, etc.).

Recommendations from unpaid caregivers

Raise awareness about available programs and services. Many of the caregivers interviewed were not aware of the services and programs available to them. Participants recommended:

- Presenting the information about programs and services in a manner that is easier to comprehend, using clear language, making the information available in multiple languages, centralizing the information, and simplifying websites so as to make it easier to learn about the resources available and how best to navigate the system.
- Mobilizing faith-based groups, community-based organizations, community coalitions, and youth as a means to disseminate information about programs and services.
- Increasing the accessibility of ASAPs by conducting outreach in the community, simplifying websites, and disseminating information in multiple ways.

Extend case management and care navigation support. Caregivers noted that it was extremely difficult to navigate the system and that the supports received did not meet their needs.

- Healthcare, social services and insurance are extremely difficult to navigate. Participants recommended expanding the availability of case managers to provide support to navigate the system.
- Participants also recommended increasing the capacity of social workers and providers to engage in active listening so as to be able to address the needs of caregivers.

- Another recommendation is to hire case managers and care navigators that speak multiple languages and are trained in providing culturally competent care.

Engage the community as key partners. Raise awareness and educate the community about the signs and symptoms of ADRD and tackle stigma.

- Many caregivers spoke about the stigma and fear associated with ADRD as a barrier to diagnosis and to seeking support. They suggested developing awareness campaigns and working with youth, police, faith-based organizations, and others to build awareness about ADRD, provide information on the signs and symptoms of ADRD for early recognition, and disseminate information on where to get help.
- All community members, including the police, have an important role to play in making sure that people with ADRD are safe. Raising community awareness about the issue and establishing mechanisms to ensure a safe return home if a person is found wandering the streets are two additional recommendations.

Bring services to the community. Residents overwhelmingly mentioned that they prefer to access services in their communities. They trust community-based resources more and those resources are also more easily accessible. Respite care for caregivers is urgently needed, both at night and during the day. Participants suggested that affordable, quality day care centers should be opened in each neighborhood to meet the needs of each community. Residents noted that there is a distrust of large hospitals in many communities, and that the preference is to seek care at community health centers. They suggested increasing the capacity of these centers to provide services to the aging population, including by hiring PCPs, neurologists, and geriatricians.

“So-called overnight care does not really exist; it is all going back to the family member.”

- Key informant interviewee

Provide subsidies to cover the gap. Many low- and middle-income families cannot afford the out-of-pocket expenses of in-home support, day care services, and residential facilities. Participants recommended subsidizing these services or increasing the maximum allowable assets and income to qualify for free or low-cost nurse aides and for long-term care plans, either at home or residential. In advanced cases of ADRD, patients may need 24-hour care. Establishing affordable wraparound care for residents with advanced dementia is needed.

Expand low-cost and free transportation options. Transportation and distance from services is an important barrier for caregivers.

- Expand the options for public or private transportation to reduce wait-times.
- Simplify the process of requesting transportation.
- Modify policies so that transportation for caregivers is also covered and available at low-cost or for free.
- Build the capacity of drivers to provide transportation for people with ADRD and their caregivers.
- Make services available in multiple languages.