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# BPHC BOLD Dementia Assessment

## Data Brief: Needs of Older Adults 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 to inform future planning efforts.

To identify and better understand care and support needs of older adults in Boston, the BOLD assessment fielded a survey of Boston social service providers (the 'Provider Survey'). Respondents included approximately 17 'frontline providers' (i.e., home-based caregivers, community-based caregivers, and other direct service providers) and 19 'other providers' (i.e., physical or behavioral healthcare providers and those providing information and referrals). The Provider Survey specifically sought to understand the needs and barriers experienced by older adults who are currently receiving these types of services. In addition, 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 were conducted 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 the Provider Survey and the qualitative data collection as it relates to the needs of older adults and adults living with or caring for persons with ADRD in Boston. The brief also highlights system-wide issues and recommendations for improving access to care.

### **Service Needs Among Older Adults in Boston**

Social service providers in Boston serve a range of populations, particularly those who are more vulnerable and with higher support needs. Within this sector, the Provider Survey targeted providers who work specifically with older adults. **Table 1** summarizes the subpopulations of older adults that the Provider Survey respondents serve through their work.

Most frequently, respondents reported working with low-income older adults (86%), older adults with clinically diagnosed Alzheimer's or related dementias (ADRD) (83%), and older adults with physical disabilities (75%). Importantly, nearly 70% of providers reported they work with persons of color and non-English speaking populations.

Data on the subpopulations served by Provider Survey respondents show that the unmet needs, barriers, and challenges and facilitators to finding and obtaining care identified in subsequent survey questions pertain not just to the general older adult population in Boston, but to populations of interest in the context of the BOLD assessment. Specifically, the results outlined below reflect the needs and challenges faced by residents living with ADRD, those at increased risk of ADRD due to socio-economic disparities (i.e., people of color, low-income older adults), and populations that face unique barriers to care (i.e., older adults with physical disabilities, non-English speakers/those with LEP). Building a more nuanced understanding of the needs and challenges faced by these populations will enable BPHC and its partners to develop a more equitable and effective strategic plan.

Table 1. Subpopulations Served (n=36)

	Frequency	Percent
Low-income older adults	31	86%
Older adults with clinically diagnosed ADRD	30	83%
Older adults with physical disabilities	27	75%
BIPOC older adults	25	69%
Non-English speakers / those with LEP	25	69%
Middle income older adults	17	47%
LGBTQ+ older adults	16	44%
Older adults who are refugees	12	33%
Other populations	4	11%
I don't know/Not reported	2	6%

DATA SOURCE: Provider Survey, 2022

NOTE: providers were asked to select all that apply, thus percentages may sum to greater than 100%

Additional context comes from the survey question that asked providers to estimate the proportion of their clients who are experiencing memory loss (**Table 2**). The majority of providers estimated that ‘some’ (19%) or ‘many’ (50%) of their clients were experiencing memory loss. Again, this highlights the relevance of the survey findings to the subpopulation of older adults in Boston who are experiencing ADRD.

Table 2. Proportion of Clients Estimated to be Experiencing Memory Loss (n=36)

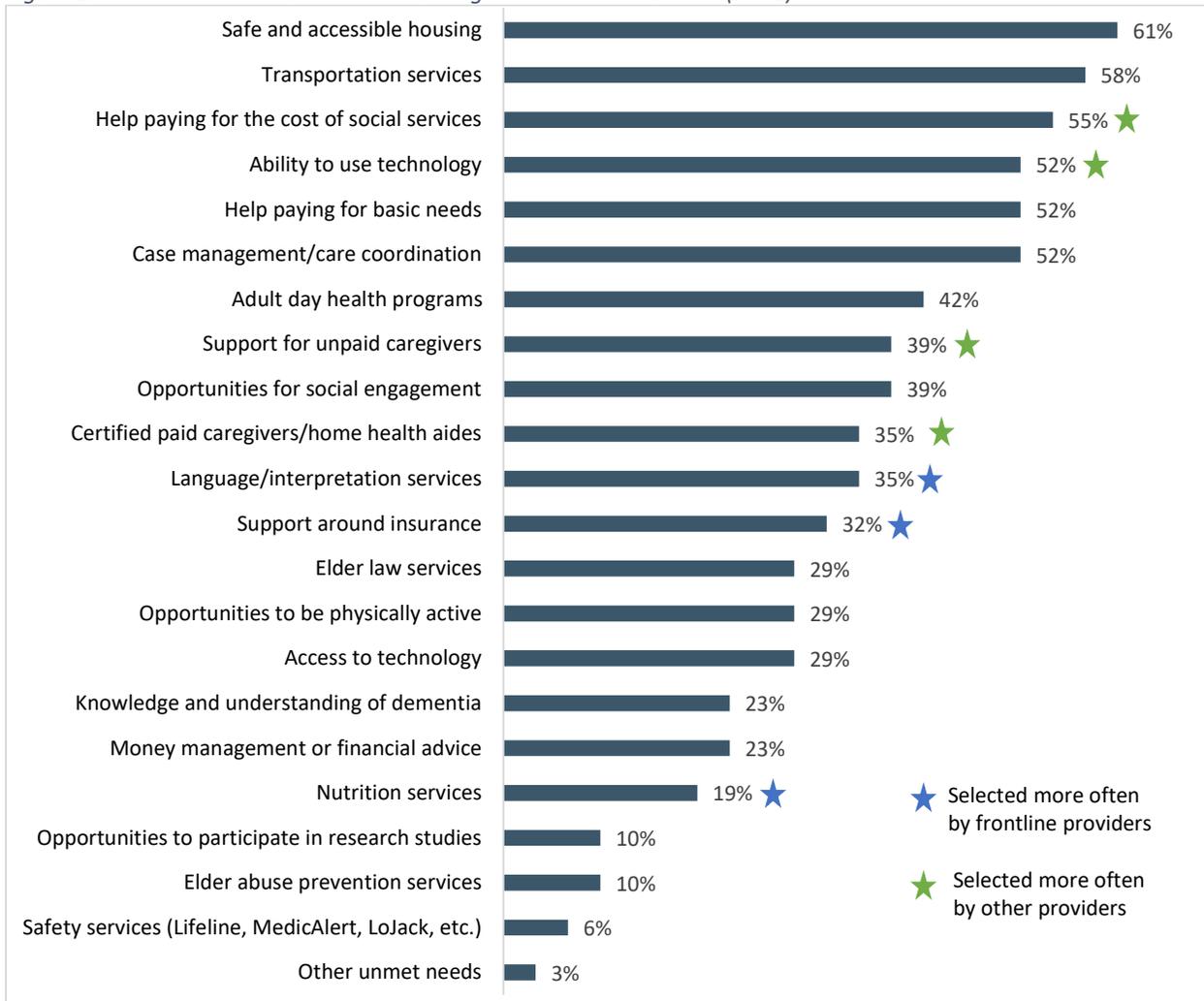
	Frequency	Percent
All of them	4	11%
Many of them	18	50%
Some of them	7	19%
A few of them	7	19%
None of them	0	0%
Don't know	0	0%

DATA SOURCE: Provider Survey, 2022

Providers were asked to identify, from an extensive list, the most common unmet needs they observe among the older adult clients they work with in Boston. As illustrated in **Figure 1**, the most frequently selected needs included ‘safe and accessible housing’ (61%) and ‘transportation services’ (58%). Other needs that were selected by more than half of providers included ‘help paying for the cost of social services’ (55%), ‘ability to use technology’ (52%), ‘help paying for basic needs’ (52%), and ‘case management/care coordination’ (52%).

Some differences were observed by type of provider. Frontline providers were more likely to select ‘language/interpretation services’, ‘support around insurance’, and ‘nutrition services’, while other providers were more likely to select ‘help paying for the cost of social services’, ‘ability to use technology’, ‘support for unpaid caregivers’, and ‘certified paid caregivers/home health aides.’ These differences likely reflect the varying insights different types of providers gain about their clients as they interact with them in unique contexts to address diverse needs.

Figure 1. Most Common Unmet Needs Among Older Adults in Boston (n=31)



DATA SOURCE: Provider Survey, 2022

NOTE: providers were asked to select all that apply, thus percentages may sum to greater than 100%

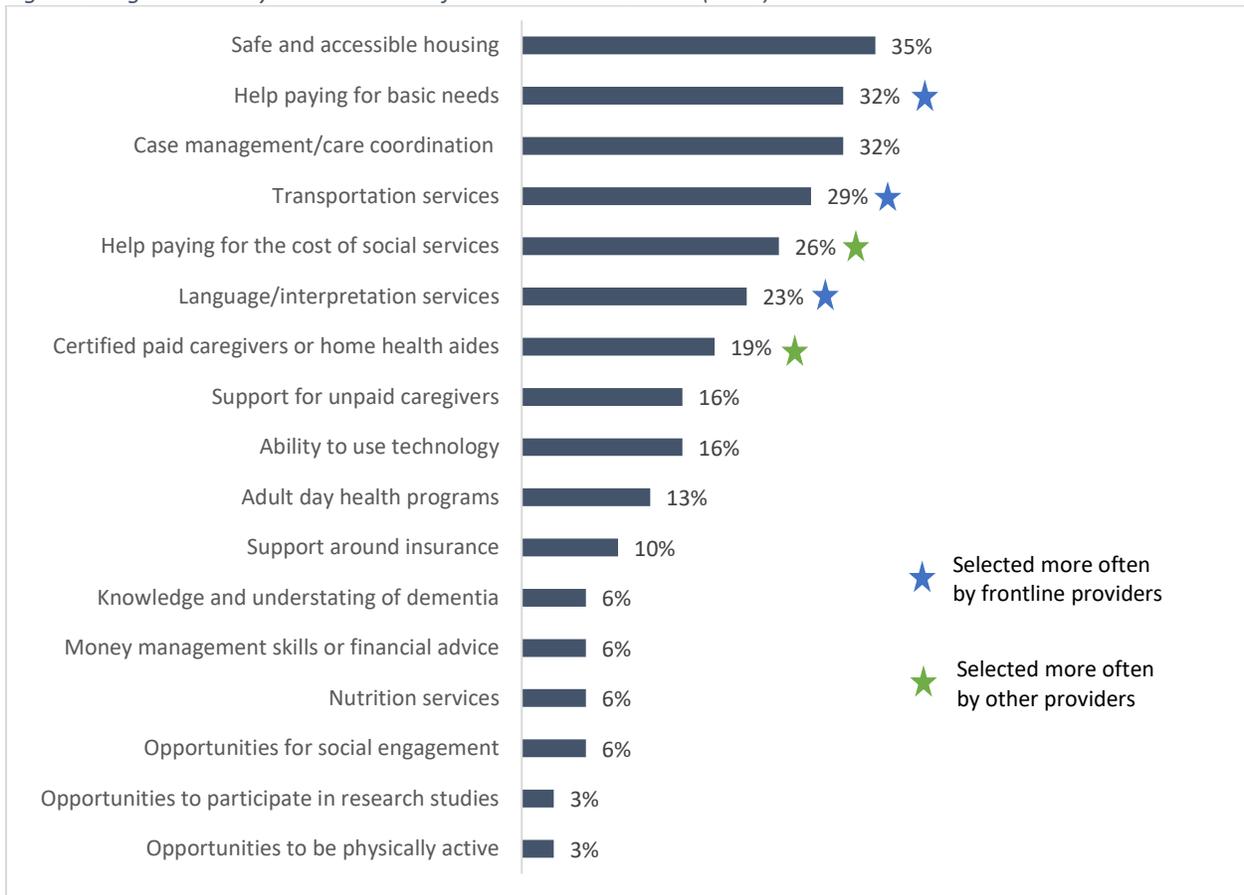
While the above survey question aimed to understand the full range of unmet needs providers observed among their older adult clients, the survey then asked respondents to narrow down their selections to the three needs that they thought were the highest priority for older adults in Boston (**Figure 2**). Like the findings above, the most frequently selected priority needs included ‘safe and accessible housing’ (35%), ‘help paying for basic needs’ (32%), ‘case management/care coordination’ (32%), ‘transportation services’ (29%), and ‘help paying for the cost of social services’ (26%).

Frontline providers were particularly likely to select ‘help paying for basic needs’, ‘transportation services’, and ‘language/interpretation services’ as priorities, while other providers were more likely to select ‘help paying for the cost of social services’ and ‘certified paid caregivers/home health aides.’

Taken together, the most common and highest priority needs align with many social determinants of health, including housing, transportation, and the financial means to afford both basic needs and support services. Findings also point to needs related to navigation of the service sector, including case management or care coordination services, and language/interpretation services. Support for unpaid

caregivers and greater access to certified paid caregivers or home health aides also appear within the top ten overall needs and priority needs.

Figure 2. Highest Priority Unmet Needs of Older Adults in Boston (n=31)



DATA SOURCE: Provider Survey, 2022

NOTE: providers were asked to select up to three, thus percentages may sum to greater than 100%; Needs not selected by any respondents are not shown.

Providers were also asked how well the social service sector in Boston is currently meeting the needs of older adults living in the community (Table 3). Findings skewed toward the negative end of the scale. Over one third responded either ‘not so well’ (31%) or ‘not well at all’ (6%), half responded ‘somewhat well’ (50%). No respondents reported the social service sector in Boston is meeting the needs of older adults ‘extremely well.’

Table 3. How Well Does the Social Service Sector in Boston Meet the Needs of Older Adults in the Community? (n=32)

	Frequency	Percent
Extremely well	0	0%
Very well	4	12%
Somewhat well	16	50%
Not so well	10	31%
Not well at all	2	6%

DATA SOURCE: Provider Survey, 2022

## Perceptions of Barriers to Care

### Lack of awareness about prevention

Many key informant interviewees and focus group participants mentioned a lack of awareness about ADRD and prevention strategies in the community. They indicated that many residents believe that memory loss is a normal part of aging and that nothing can be done to prevent it. Participants emphasized the need to inform community members of all ages about prevention and early signs of dementia. As one participant explained, *“There is a need to educate younger residents, including high school students, about the warning signs of dementia so they can recognize these signs in elder relatives who may live in their home.”*

### Structural barriers to engaging in prevention

Participants noted that, despite knowledge, many residents face barriers to engaging in healthy lifestyles. Not surprisingly, cardiovascular comorbidities, including diabetes and hypertension, are prevalent among residents with ADRD. Echoing findings from the Provider Survey regarding the need for safe and accessible housing, many residents face housing instability and homelessness. As a key informant interviewee providing social services for Asian residents noted, *“The number one question people ask about is housing.”* Many others experience food insecurity and/or cannot afford fresh fruits and vegetables. Participants mentioned that the nutritional quality of the food provided by meal services and food pantries is deficient and not adapted to the cultural diversity of Boston residents. Other residents are unable to exercise due to time, physical, and/or environmental constraints. A focus group participant explained that the neighborhoods where low-income residents live are unsafe and have uneven sidewalks, making walking difficult for those with an unstable gait. Participants indicated the need for more fitness and exercise programs.

### Barriers to screening and early diagnosis

Some participants noted that there had been important advances in raising awareness about ADRD in Boston led by the Alzheimer’s Association, the Age Strong Commission, and Dementia Friends, a program in which faith-based organizations (FBOs) and community-based organizations (CBOs) collaborate to host education events focused on increasing awareness of and destigmatizing ADRD. However, they also highlighted that more work remains to be done.

***“I also have a close friend who is beginning to have memory loss and is always asking for names of people he regularly works with – he says, ‘Why can’t I remember his name?’ and I’m like ‘That’s a good question.’ And he just dismisses it and says he’s getting old.” - Focus group participant***

One barrier to early diagnosis mentioned was the *normalization of memory loss in older age* both by community members and healthcare providers. A key informant interviewee described the experience of two Boston residents ***“both men saw it as normal signs of aging, then saw their parents making mistakes they normally wouldn’t make, like leaving a stove on or walking out of the house and not just leaving the door unlocked but leaving it open, that set off warning bells.”***

Another barrier mentioned was *fear*. Some participants indicated that most community members are not aware that cognitive decline can be slowed down and equate a dementia diagnosis with a death sentence. Therefore, they are not inclined to seek screening. They also noted that there is significant

*stigma* surrounding conditions that affect memory or cognition. Many people affected by memory loss are ashamed of admitting that they have a problem as they fear they will be considered ‘crazy’ or will lose their independence. It was also evident from these discussions that confusion around Alzheimer’s disease as a mental health disorder vs. a neurological disorder is common.

*Unclear information.* An issue discussed extensively by participants was not knowing where to seek help for themselves or a loved one. Residents said that they first sought information online and from family and friends. People noted that websites on ADRD were difficult to navigate and had no clear information on where to obtain help. A participant recommended, “Talk to us as if we’re not doctors and we’re not website engineers.” Also, many people do not have a computer and/or internet at home, have sight problems, and/or are not digitally savvy. Further, information online is not always available in languages other than English.

***“[My wife] said to me we should all get a baseline. I don’t know what that means, where to get it, where to ask for it.” - Focus group participant***

*Issues with Primary Care Providers (PCPs).* Participants noted that the PCP at the neighborhood community health center is frequently the first point of contact for those with health insurance, often as part of an annual check-up. However, several barriers to screening and diagnosis emerged even for those who have a PCP:

- Many residents, including residents of color, *do not discuss memory loss with their PCP* either because they are ashamed or because they don’t consider it a serious problem.
- When patients do discuss memory loss with their PCPs, they noted that some *PCPs dismiss the symptoms as a normal part of aging.* Participants often indicated that PCPs did not conduct the appropriate screening tests or make referrals to specialists that could lead to a diagnosis.
- On the other hand, PCPs interviewed indicated that there is insufficient time in a 15-minute visit to conduct screenings given competing health priorities.
- Another issue mentioned were the long delays in obtaining appointments with PCPs. As expressed by a resident, ***“In terms of screening, just in general it is difficult to get appointments for anything now, even primary care.”***

## **Perceived Support Needs for Older Adults with Dementia**

### Post diagnosis support

As a progressive condition, people living with ADRD and their caregivers are often unprepared. They do not know what to expect nor what services are available to them.

*Unclear communications.* Some participants noted that providers did not provide clear information about the diagnosis, what it meant, what to expect, and where to seek support. Participants indicated that communication barriers were worse for foreign-born patients (consistent with results from the Provider Survey showing that frontline providers, in particular, view language and interpretation services as an unmet need for Boston’s older adult population). A social services provider noted of Asian residents, ***“Older adults tend to be very polite, do not want to offend people, so they are just polite, take the resource then go ask someone else, they do not advocate for themselves or ask for [an] interpreter.”***

*Care coordination.* Care coordination was among the top three unmet needs for older adults identified by respondents to the Provider Survey. Qualitative data support this finding. Most caregiver participants described multiple obstacles to navigating care for their relatives and obtaining the needed supports. First, few of the caregivers we interviewed indicated taking their relatives to any programs or even knowing about the programs available. Second, they indicated that qualifying for respite care, long-term care, and adult day care services was onerous and many said that their relatives were not eligible for subsidized care. One caregiver described, **“Someone came to my house and took all my information to see if I qualified for services, they mentioned a sliding scale, but then they closed my case and never followed up.”** Another caregiver noted that dealing with ASAPs was challenging saying, **“I had a lot of trouble connecting with services [personal care assistance] for my husband. I felt like I was bounced around through agencies.”**

Staff in community-based health organizations (CBOs) remarked that case managers or care navigators facilitated access to services. However, they noted long delays in obtaining referrals from PCPs and approvals from insurance companies. Participants recommended reducing the turnaround time for referrals from PCPs to CBOs and simplifying the approval process.

Participants indicated that planning appointments and programs around established routines was also complicated. In relation to Memory Cafés, a social services provider illustrated the point, **“It is challenging because clients need to work and do other things. We used to have a Memory Café; people wanted it but didn’t show up due to scheduling conflicts. You need to work around that to support the families.”**

The provider survey included several questions designed to better understand how older adults and/or caregivers currently seek out and engage with support services. When asked how most of their clients first connected to them/their agency for services (**Table 4**), providers indicated that self-referrals (61%) were just as common as referrals from healthcare providers (61%). However, many providers also reported referrals coming from social service organizations (39%), mental health providers (26%), and community centers (26%), as well as other referral sources (29%).

*Table 4. How Do Most Older Adults and/or Their Caregivers First Connect with You or Your Agency? (n=31)*

	Frequency	Percent
Self-referral	19	61%
Referred by healthcare provider	19	61%
Referred by a social service organization	12	39%
Referred by mental health provider	8	26%
Referred by a community center	8	26%
Other sources of referral	9	29%

*DATA SOURCE: Provider Survey, 2022*

*NOTE: providers were asked to select all that apply, thus percentages may sum to greater than 100%*

The findings above suggest that many older adults in Boston are seeking care and support services on their own. The survey asked providers how hard or easy they perceive it to be for older adults to *find* care in Boston. Per the survey, ‘finding services’ was defined as an individual knowing where to go or who to talk to in order to locate the care and support services they are looking for. As detailed in **Table 5**, none of the providers reported that it was easy. Rather, all reported that finding care was either ‘somewhat hard’ (55%) or ‘very hard’ (45%) for older adults in Boston.

Table 5. How Hard or Easy is it for Older Adults and/or Their Caregivers to FIND Care? (n=31)

	Frequency	Percent
Extremely hard	0	0%
Very hard	14	45%
Somewhat hard	17	55%
Somewhat easy	0	0%
Very easy	0	0%
Extremely easy	0	0%

DATA SOURCE: Provider Survey, 2022

Providers were also asked how hard or easy they perceive it to be for older adults to *obtain* care in Boston (**Table 6**). Distinct from ‘finding’ care, the survey defined ‘obtaining care’ as an individual’s ability to meet eligibility criteria, successfully sign-up, pay for, or otherwise begin receiving care and support services. While a few providers (n=3) reported obtaining care was either ‘very easy’ (3%) or ‘somewhat easy’ (6%), the majority reported it was either ‘somewhat hard’ (48%), ‘very hard’ (32%), or ‘extremely hard’ (10%) to obtain care or support services in Boston.

Table 6. How Hard or Easy is it for Older Adults and/or Their Caregivers to OBTAIN Care?

	Frequency	Percent
Extremely hard	3	10%
Very hard	10	32%
Somewhat hard	15	48%
Somewhat easy	2	6%
Very easy	1	3%
Extremely easy	0	0%

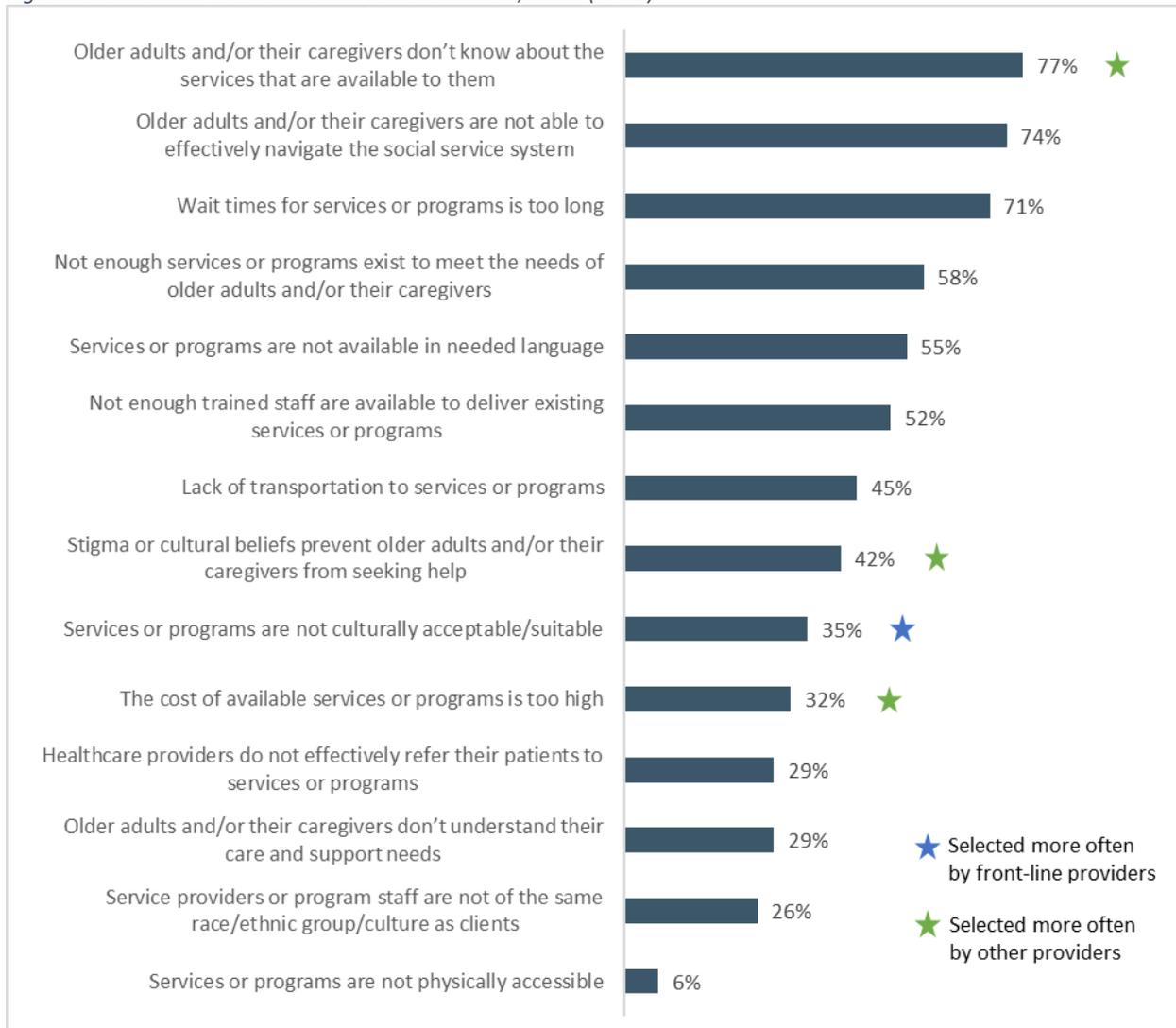
DATA SOURCE: Provider Survey, 2022

To gain a better understanding of why finding and/or obtaining care is challenging, the survey asked providers to identify, from an extensive list, the barriers older adults face when trying to find or obtain care and support services in Boston.

As illustrated in **Figure 3**, 77% of providers selected ‘older adults and/or their caregivers don’t know about the services that are available to them’ and 74% selected ‘older adults and/or their caregivers are not able to effectively navigate the social service system’. Other frequently identified barriers included long wait times (71%), not enough programs or services (58%), and not enough trained staff to deliver/run existing services or programs (52%).

Additionally, between one-third and one-half of providers selected barriers that related to the linguistic or cultural needs of clients, specifically ‘services or programs are not available in needed language’ (55%), ‘services or programs are not culturally acceptable/suitable’ (35%), and ‘stigma or cultural beliefs prevent older adults and/or their caregivers from seeking help’ (42%).

Figure 3. Barriers to FINDING and OBTAINING Care, Total (n=31)



DATA SOURCE: Provider Survey, 2022

NOTE: providers were asked to select all that apply, thus percentages may sum to greater than 100%

### Specific needs for people living with ADRD

**Mental health care and ADRD.** Many people with ADRD experience comorbid mental health disorders. However, interview and focus group participants noted that there are insufficient behavioral health providers trained in treating mental health conditions, such as anxiety and depression, among people living with ADRD and treatments are not always evidence based. Another gap is cultural competence to address stigma surrounding mental health disorders. Caregivers noted being offended when their relatives with ADRD were referred to a psychiatrist.

**Supports for people in the early stages of dementia.** Residents in the early stages of dementia often do not qualify for services and supports as they are not yet facing safety issues, however, it is increasingly difficult for them to maintain a job or complete daily routines. As a caregiver noted, **“a lot of times they are not there yet in terms of becoming unsafe, but it would really benefit themselves and their family”** to have access to day care. Participants also noted that support groups are mostly for caregivers rather

than for people living with ADRD. As a key informant interviewee noted, *“This whole dementia journey is made a little bit lighter if people also have a chance to connect with peers who also have dementia.”*

*Support for people with other dementias.* Participants noted that many services are geared toward people with Alzheimer’s disease and there are fewer services available for those afflicted with other types of dementia. They indicated that there were insufficient specialized services available for people with early onset dementia and/or with atypical symptoms. Existing programming does not meet the needs of these patients.

*Support for people with advanced dementia.* Care needs advance as dementia progresses. More programs are needed to involve patients in promising clinical trials and in services to slow down decline. It is also necessary to extend affordable respite care options for caregivers, such as overnight programs.

## **Overarching issues**

### Cost and insurance issues

Many participants mentioned difficulties affording the out-of-pocket costs of care and treatment for loved ones with dementia. Caregivers noted that, even though they would welcome respite care during the day and at night, they could not afford it and were frustrated by this. One caregiver summed up the sentiment of most, *“The resources are there, but you almost never qualify, even if you live in the community. You have to jump through all these hoops . . . it’s almost within reach but then you almost never qualify.”*

Caregivers noted that there is a gap for middle income residents who do not qualify for MassHealth. One caregiver described her experience searching for facilities for her husband with dementia, *“We visited a beautiful facility, but it cost \$450 per day. If you cannot afford to pay out of pocket, you have very limited options. It is not fair for residents who worked all their lives and contributed so much to society.”* They noted that if you owned a home or had a 401K you would not qualify for MassHealth. As a caregiver expressed, *“If you just have your home and that’s all you have the person is not rich, and they really can’t take money out of that home and pay for these things.”* Further, other resources, such as adult diapers, are generally not covered by insurance.

Another group that faces significant access barriers are undocumented residents, who are not eligible for MassHealth or public services, including adult day care centers. As a result, family members must stop working to stay at home with relatives.

Residents expressed that navigating insurance was very complicated. One participant summed up the sentiment, *“It is a full-time job. Once you figure it out and get components of it, it’s great. But it is not the easiest thing to negotiate.”*

### Quality

Caregivers noted the uneven quality of adult day care centers and residential facilities. Participants described instances of unqualified providers, elder abuse, and safety breaches. One focus group participant described their loved one leaving an adult day care center on their own due to lack of supervision. Others noted that facilities did not provide stimulation and care aimed at slowing down cognitive loss. Residents highlighted the issue of equity, noting that the better facilities were unaffordable and located in the suburbs, far away from where they lived.

They worried that increasing care demands for an aging population would further increase the quality gap. In the words of a Boston resident, *“As demand increases, more places will open up, but some will be lower quality. Communities of color will be disproportionately affected – there are already few adult day-care options in Mattapan and Dorchester.”*

#### Insufficient workforce capacity

Focus group and interview participants highlighted the need for more qualified healthcare and allied health providers, particularly those trained in working with older adults with ADRD and who can provide culturally competent care. As one CBO staff member noted, *“We have struggled to hire all bilingual staff.”* Many facilities ask the patients to come with an interpreter. As a key informant interviewee described, *“We have to build that capacity and educate frontline professionals on how to work with people who don’t speak the language.”*

#### **Recommendations for improving access**

The City of Boston has a wealth of programs, resources, and partners that can provide support for people with ADRD and their caregivers. However, many residents are not aware of these resources. Facilitating access to information is a critical step.

Educate and empower communities. Focus group participants and interviewees recommended organizing educational activities and communications campaigns to empower communities to address ADRD. The following are some specific recommendations that emerged from discussions:

- Develop campaigns to increase community awareness of early warning signs; to promote screening and early diagnosis; to address fear and stigma; and to foster community support for persons living with ADRD.
- Use positive framing for these campaigns with a focus on empowering people living with ADRD, on the treatment options, and on the importance of early diagnosis to slow down cognitive decline.
- Target community members of all ages, including youth, because: 1) lifestyle is important for prevention; and 2) it is usually family members who detect a problem and help the patient access care.
- Organize educational activities on an ongoing basis to broadly disseminate messages about prevention and available treatment and support services.
- Use 5-6 clear messages, with information on available resources and where to seek help (e.g., a phone number or hotline).
- Consolidate and simplify information. In the words of a key informant, *“This is New England. This is Boston. We trust our medical establishments, if we had a direct connection, if we had something that was simplified to connect with people or resources quickly and easily then people would use it.”*
- Use multiple modes of communication (online, print, word of mouth).
- Partner with faith-based-organizations, community-based organizations, schools, police, community health care centers and other local institutions to disseminate messages about prevention and available treatment and support services.

Universal screening. ADRD screenings are usually triggered by the patient or a family member, or by an emergency (e.g., fall injury or cardiovascular accident). Participants recommended making screenings for ADRD an integral part of geriatric primary care, noting that annual physical visits should be long enough to conduct comprehensive geriatric assessments.

Dementia Friends implements a promising model consisting of organizing screenings in partnership with FBOs, CBOs, and other local institutions. On the importance of local screenings, a CBO staff member noted that health screenings are *“very important because we are not just doing screening, we are building connections, building trust in the community . . . trust is the key word.”*

Engage communities – come to where the people are. Most participants recommended mobilizing the community to address ADRD at all stages.

- Through personal stories, focus group and interview participants illustrated the importance of having neighbors, police, and others sensitized to ensure that people with ADRD came home safely if they wandered off.
- They also noted how community healthcare centers are the first point of care access for many Boston residents. As the first point of contact, providers at community healthcare centers can play a critical role in building awareness of the condition and facilitate early diagnosis.
- Participants emphasized how important family members, including young relatives, are in linking people with ADRD to care; thus, the importance of developing messages and education campaigns for all.

Competent multicultural workforce. Expansion of the workforce is imperative to increase access. In that regard, there is a need for more geriatricians and neurologists, as well as primary care providers trained in geriatrics. There is also a dearth of nurse aides and home attendants that can provide care. Given the diverse population of Boston, a workforce that is trained in culturally competent care, care of LGBTQ+ residents, and that speaks multiple languages is needed.

Health insurance policies. Massachusetts has one of the most advanced healthcare systems in the US. However, cost and insurance coverage limitations still pose barriers to access. Revising policies to raise the cap on assets for MassHealth eligibility, and expanding quality, affordable day care centers and residential facilities would be an important step to reduce the access gap. Residents suggested instituting a sliding scale or amending existing sliding scales for such services to improve/expand program eligibility.

Monitoring and evaluating quality. Residents were concerned about inequities in quality of services across neighborhoods, with subpar facilities located in neighborhoods where the majority of residents are people of color. Participants indicated that the City of Boston has a role in developing quality guidelines for care facilities serving people with ADRD and monitoring facilities’ performance in the context of these guidelines.