

October 18, 2022

BPHC BOLD Dementia Assessment

Data Brief: Ability of the Social Service Sector in Boston to Meet the Needs of Older Adults

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.

To better understand the ways in which healthcare and social service providers in Boston collaborate to support individuals with Alzheimer's disease and related dementias (ADRD) and their caregivers, the impact of this collaboration, and how it can be expanded upon to improve outcomes, 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). 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 ADRD and their caregivers. This data brief presents the results from the Provider Survey and the qualitative data collection as it relates to collaboration, coordination, and capacity within Boston's social service sector.

The needs of older adults living with ADRD and their caregivers are complex and require a range of supports beyond the care offered by providers and organizations specializing in memory loss. Individuals living with ADRD may need help managing medications and treatment for chronic comorbidities, those in the early stages of memory loss may benefit from social engagement through adult care centers and similar programs, while law enforcement and other public sector employees must be prepared to protect the safety of individuals who wander. Older adult caregivers to individuals with ADRD may have complex medical needs and conditions of their own to manage, while caregivers in the workforce may experience a negative impact on employment and financial security, necessitating connections to other social services, such as food and housing support. In addition, there is a need for specialists with sufficient cultural competence to meet the needs of individuals with ADRD and caregivers from a range of intersectional backgrounds (e.g., people of color, individuals with limited English proficiency, and LGBTQIA+ individuals).

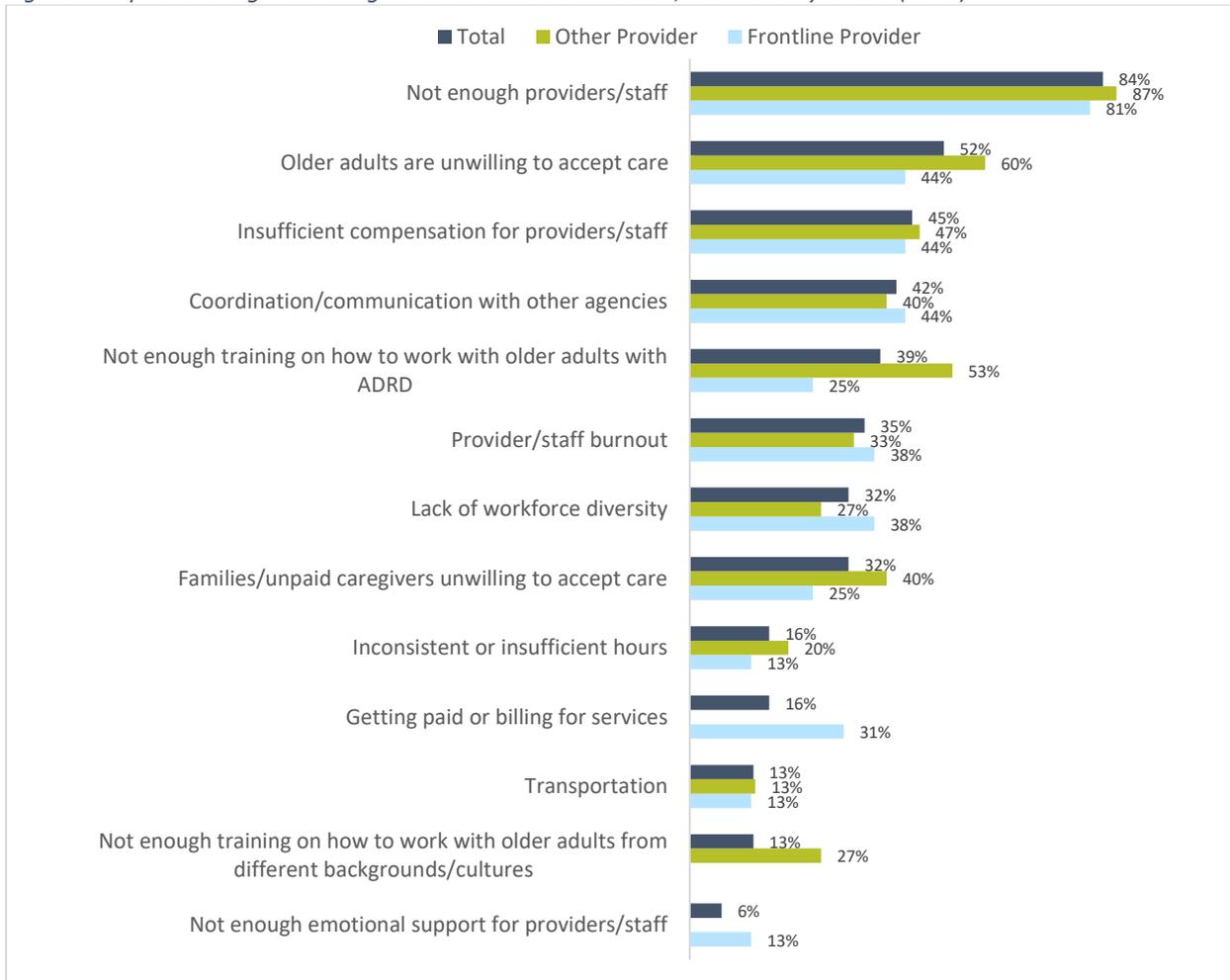
Challenges Faced by Paid Caregivers and Service Provider Workforce

Figure 1 shows the top challenges faced when working with older adults in Boston, as reported by Provider Survey respondents overall and by sector (frontline vs. other providers). By far, the most frequently reported concerns among respondents in both groups was not having enough providers and staff to meet the needs of Boston's older adult population (84% overall). The next most frequent challenges included older adults being unwilling to accept care (52% overall), insufficient compensation (45% overall), and coordination/communication with other agencies (42% overall). These common challenges highlight the complexity inherent to social service jobs, individuals must manage systems-level issues such as staffing and coordination of care, and the interpersonal challenges of connecting to clients and meeting their social or emotional needs.

Differences in challenges experienced by 'frontline' versus 'other providers' are also telling. Notably, none of the 'frontline providers' reported that insufficient training on how to work with older adults from different backgrounds/cultures was a challenge, while nearly 30% of 'other providers' reported this

was a challenge. Additionally, about half of ‘other providers’ identified a lack of training on how to work with older adults with ADRD as a challenge compared with 25% of ‘frontline providers.’ Conversely, no one from the ‘other providers’ group reported challenges with billing for services or receiving insufficient emotional support, while 31% and 13% of ‘frontline providers’ reported these challenges, respectively.

Figure 1. Top 5 Challenges Working with Older Adults in Boston, Total and By Sector (n=31)



DATA SOURCE: Provider Survey, 2022

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

In terms of qualitative data collection, scarcity of trained, paid caregivers was mentioned as a challenge by focus group and interview participants. Residents noted that it was particularly difficult to find paid caregivers willing to work in certain neighborhoods, for clients requiring part-time help, and for non-English speaking clients. Participants agreed that more linguistically diverse frontline providers are needed, specifically those trained in working with older adults with ADRD.

The challenge of older adults not accepting care was also a theme that emerged in qualitative discussions as a few participants described that patients in the early stages of cognitive decline refuse to be evaluated and that those in later stages can become violent and aggressive.

Qualitative discussions also delved into the importance of and need for provider training. Participants mentioned that several training opportunities were available to paid caregivers in Boston, including those organized by the Alzheimer’s Association and the Dominican Development Center, among others.

However, Participants indicated that more training of primary care providers in the diagnosis and management of patients with ADRD is sorely needed. Further, several participants noted that frontline providers trained to work with people with ADRD were scarce. They remarked on the need for more skills-based trainings on ADRD and caring for older adults with ADRD, on de-escalation, and on providing culturally appropriate and respectful care.

*“A lot of us, myself included, feel ill-equipped to diagnose and manage patients with ADRD”
– Primary care provider*

Other issues that came up during qualitative discussions were the need to standardize trainings across agencies and to offer them on a regular basis to reinforce concepts. One challenge underscored by participants was that paid in-home caregivers are expected to participate in trainings on their own time. Participants recommended compensating caregivers for participating in professional development by either providing bonuses or increasing wages following training.

In line with survey findings, where over one third of respondents identified provider or staff burnout as a challenge to their work (**Figure 1**), participants in qualitative discussions described the emotional toll of working in caregiving, particularly caregiving for people with ADRD. They mentioned a lack of infrastructure in place to ensure the wellbeing of paid frontline providers, who mainly rely on their own informal social and peer support groups. Discussions further highlighted that the reality of having too few frontline providers results in long waiting times for clients to access the supports they need and contributes to provider burnout. This scenario was particularly evident in the context of the COVID-19 pandemic which severely worsened working conditions. Participants noted that being a frontline provider is a high-stress, low-wage, low-security job. As such, participants recommended improving the working conditions of frontline providers to increase workforce capacity and retention, as detailed below.

Capacity of the Social Service Sector

With over 80% of Provider Survey respondents reporting lack of providers/staff as the top challenge to working with older adults in Boston, it is unsurprising that the majority of respondents (71%) disagreed or strongly disagreed that the social service sector in Boston has enough capacity to meet the needs of older adult residents, while just 16% of respondents strongly agreed or agreed with this statement (**Table 1**).

Table 1. Percent That Agree/Disagree That the Social Service Sector in Boston has Enough Capacity to Meet the Needs of Older Adult Residents (n=31)

| | Percent |
|-------------------|---------|
| Strongly agree | 10% |
| Agree | 6% |
| Disagree | 39% |
| Strongly disagree | 32% |
| I don't know | 13% |

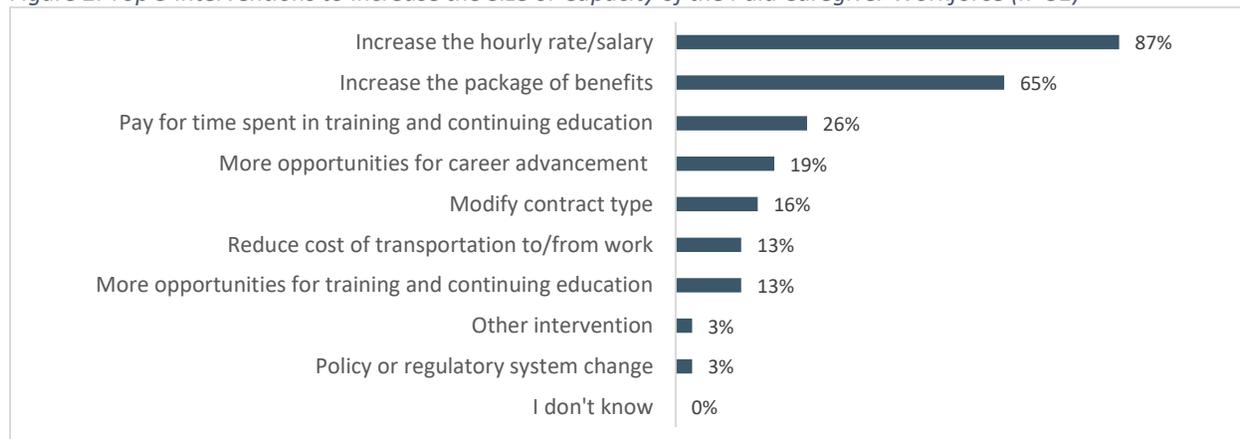
DATA SOURCE: Provider Survey, 2022

“You definitely meet home care workers who are 80 years and still delivering care, it’s just their calling, but also because they have the financial need to do so.”

– Key informant interviewee

In terms of addressing workforce size and capacity, the paid caregiver workforce (e.g., home health aides, personal care attendants, adult day care center staff, etc.) is a critical point of intervention as paid caregivers are likely to have the most frequent, consistent, and extended contact with older adults with ADRD. The top three recommendations Provider Survey respondents identified to increase the size and capacity of the paid caregiver workforce in Boston all centered around improving compensation for paid caregivers (**Figure 2**). Recommendations included: increasing caregivers’ hourly rate/salary (87%), increasing the package of benefits for paid caregivers (65%), and paying caregivers for time spent in training and continuing education (26%).

Figure 2. Top 3 Interventions to Increase the Size or Capacity of the Paid Caregiver Workforce (n=31)



DATA SOURCE: Provider Survey, 2022

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

Similar findings emerged from the qualitative data. Participants provided the following specific recommendations to increase the size and capacity of the paid caregiver workforce: increasing wages; offering a competitive benefits package, such as health insurance, sick and family leave, and social security contributions/retirement security; taking steps to improve worker safety, e.g., harassment

protection, provision of PPE, etc.; and ensuring a professional career path with paid opportunities for professional development.

Participants noted that since employers do not currently offer health insurance, many frontline in-home care providers are covered by MassHealth and thus can only work a limited number of hours in order to meet income eligibility. It is important to note that most members of this workforce are women of color, many aging themselves, and poor working conditions exacerbate existing racial/ethnic and gender disparities.

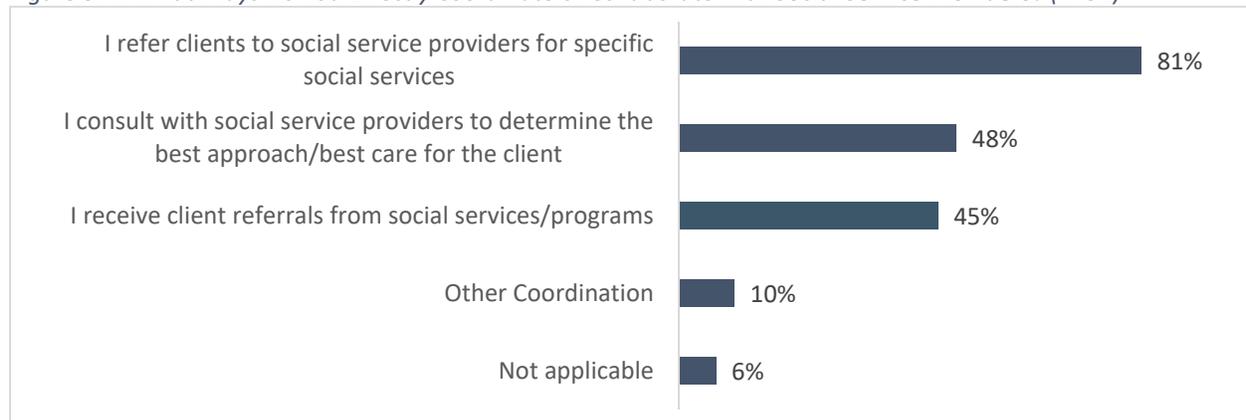
“Home care workers are often lauded as heroes but are not compensated as such.”

– Key informant interviewee

Collaboration and Coordination Across Sectors in Boston

Collaboration between healthcare and social service providers across sectors is critical to meet the needs of older adults with ADRD and their caregivers. Most Provider Survey respondents (81%) reported that they refer clients to social service providers for specific social services. Around half (48%) reported that they consult with social service providers on the best approach to care for their clients, and 45% receive client referrals from social service programs (**Figure 3**).

*Figure 3. In What Ways Do You Directly Coordinate or Collaborate with **Social Service Providers**? (n=31)*



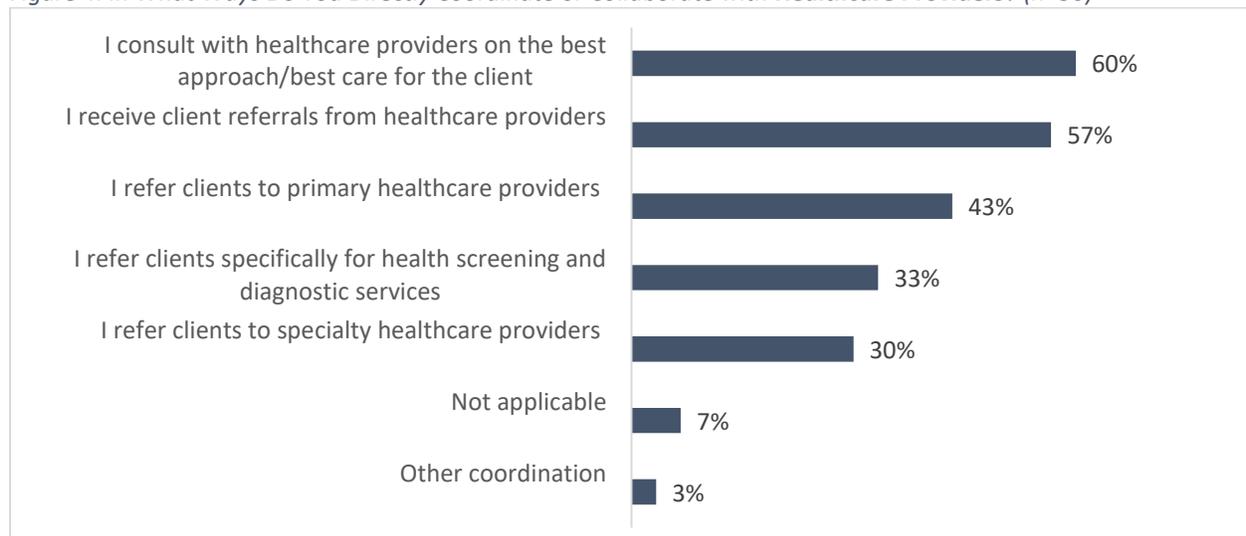
DATA SOURCE: Provider Survey, 2022

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

In contrast, less than half of Provider Survey respondents (43%) reported referring clients to primary healthcare providers, while less than one third (30%) reported referring clients to specialty providers.

More than half consult with healthcare providers on the best approach to care for their clients (60%) and receive referrals from healthcare providers (57%) (**Figure 4**).

Figure 4. In What Ways Do You Directly Coordinate or Collaborate with **Healthcare Providers**? (n=30)



DATA SOURCE: Provider Survey, 2022

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

Notably, none of the respondents to the Provider Survey described their collaborations with social service and/or healthcare providers as “extremely effective” (**Table 2**). Over half (55%) of respondents did describe their collaborations as “very effective,” while an additional 38% described their collaborations as “moderately” or “slightly effective.” On a positive note, no respondents described their collaborations as “not at all effective.”

Table 2. How Effective is Your Coordination/Collaboration with Social Service and/or Healthcare Providers (n=31)

| | Percent |
|----------------------|---------|
| Extremely effective | 0% |
| Very effective | 55% |
| Moderately effective | 19% |
| Slightly effective | 19% |
| Not at all effective | 0% |
| I don't know | 6% |
| Not applicable | 0% |

DATA SOURCE: Provider Survey, 2022

Table 3 shows the percentage of Provider Survey respondents who reported whether more collaboration or coordination would help them serve their clients better. Although responses were mixed regarding the effectiveness of existing collaborations with social service and healthcare providers, respondents largely agreed that additional collaboration would help “a lot” or “somewhat” (97%). Just 3% of respondents did not know whether additional collaboration or coordination would help them serve their clients better; no respondents reported that additional collaboration would not be helpful.

Table 3. *Would More Collaboration or Coordination Help You Serve Your Clients Better? (n=31)*

| | Percent |
|-----------------------------|---------|
| Yes, it would help a lot | 68% |
| Yes, it would help somewhat | 29% |
| No, it would not help | 0% |
| Other | 0% |
| I don't know | 3% |

DATA SOURCE: *Provider Survey, 2022*

Participants in qualitative discussions mentioned that many collaborations and partnerships exist between the City of Boston, hospitals, service providers, community/faith-based organizations, and the Alzheimer’s Association to meet the needs of the city’s older adults. Despite these efforts, they also highlighted problems with care coordination, including a lack of communication between healthcare and social service providers and low awareness of available programs. They also indicated that insurance referral requirements to obtain specialized care and at-home services further delay access to needed care and support.

Participants mentioned that having multilingual case managers or care navigators to coordinate care across multiple providers, alert residents to available programs, and provide support with insurance issues can be a game changer for patients with ADRD and their families. In addition, participants highlighted the important role of emergency responders, such as police, firefighters, and EMTs, in helping to ensure the safety of people with ADRD. Residents suggested increasing coordination between first responders and providers working with those with ADRD and building their capacity to safely respond to emergencies involving older adults with cognitive loss, including strengthening violence de-escalation skills.