Massachusetts Respite Innovation Grants

Final Evaluation Report

June 18, 2025

Objectives

- Overview of Evaluation Methods
- Collective Impact
- Categories of Respite Innovations
- Lessons Learned
- Caregiver Feedback

Project Background and Evaluation Methodology

MA Respite Innovations Grants Initiative

MA leverage one-time HCBS ARPA funding to:

- **Enhance, improve, expand** and/or reorganize the way that Respite is currently provided
- Identify **promising practices** to relieve caregivers
- **Close service gaps**
- Provide **person-centered** respite

Evaluation can provide insight on long term policy and procedural changes

MA Respite Innovations Grants Overview

- Competitive Request for Applications

- Focus on the Caregiver, not the type of respite service proved

167 Applicants	→	40 Grantees

$42 M	→	$18 M
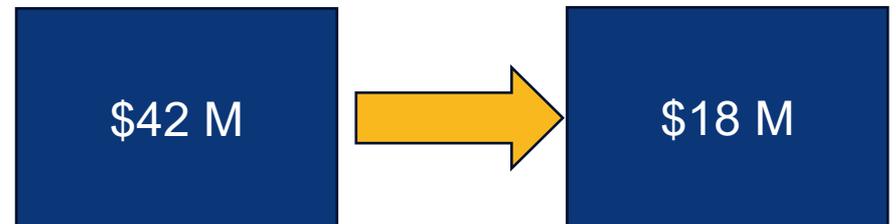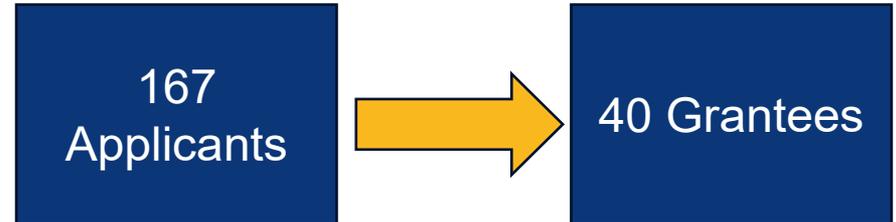
Respite Grantee Overview

- Develop, and implement new or enhanced **innovative models** of Respite service delivery.

- Provide innovative**, high quality, person-centered Respite services** to provide relief to Caregivers while providing a meaningful, safe, enjoyable experience for the care recipient.

- Provide an **inclusive, diverse, equitabl**e plan for the provision of Respite services

- **Recruit** and **retain** Respite workers in innovative ways.

- Assess programs and **evaluate outcome** measures/metrics to determine efficiency and efficacy of pilots.

Additional Evaluation Methods

Bi-Annual Reports
February 2024 – March 2025

Quarterly Learning Communities
April 2024 – March 2025

Focus Groups
November 2025

Caregiver Survey
February 2025

Impact

Total Caregivers Supported: 7,241

1,718 (24%) Caregivers received respite for the first time

1,981 (27%) Caregivers were over the age of 65

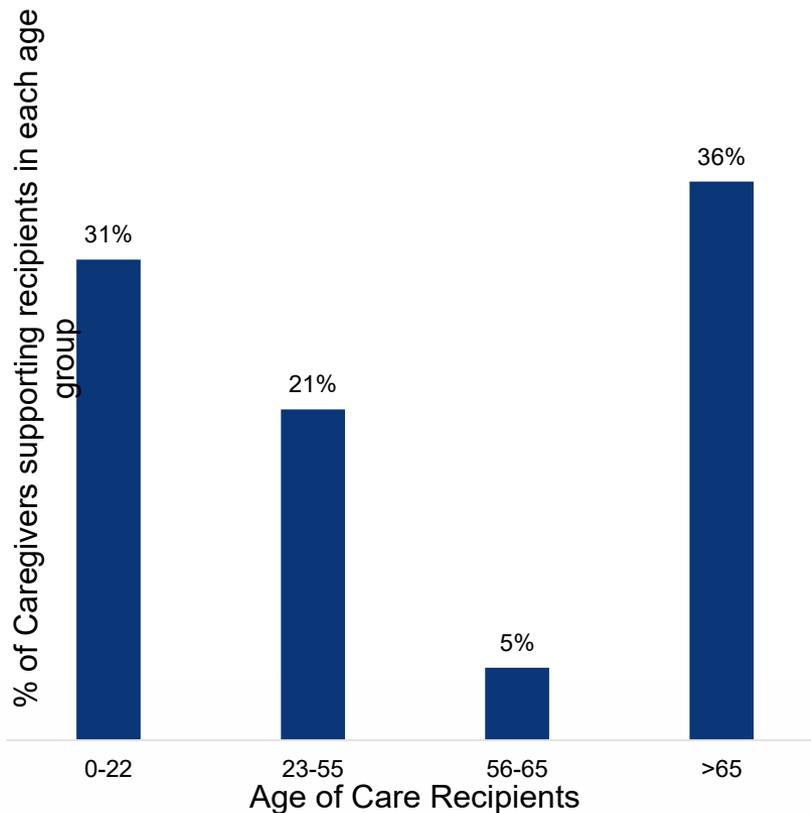1,151 (16%) Caregivers spoke a primary language other than English

1,544 (21%) Caregivers supported loved ones with complex health conditions

Caregivers are supporting individuals across the lifespan

Avg. Percentage of Caregivers Serving Care Recipients by Age Group

Bar chart — % of Caregivers supporting recipients in each age group (y-axis) vs. Age of Care Recipients (x-axis):
- 0-22: 31%
- 23-55: 21%
- 56-65: 5%
- >65: 36%

"I am a single grandparent raising a grandchild and have an 85 year old mom I need to travel to see and help care for."

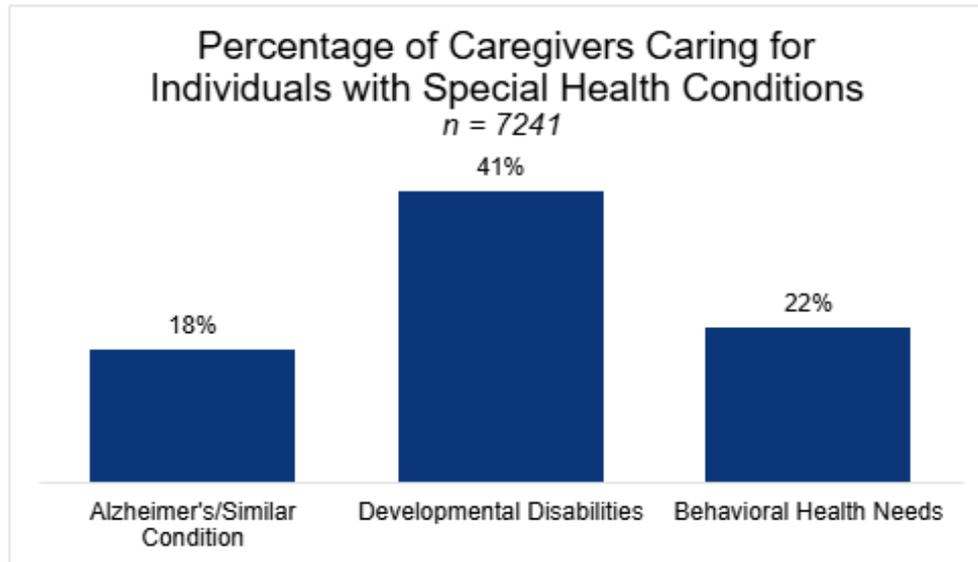"I am taking care of my mom and working a full-time job I am tired on a daily basis."

"My Young Adult always loves to go to the Respite Program when available."

Source: Final Performance Report

Source: Caregiver Survey

Caregivers are key players in our healthcare system. They support loved ones with complex conditions

Percentage of Caregivers Caring for Individuals with Special Health Conditions
n = 7241

Condition	Percentage
Alzheimer's/Similar Condition	18%
Developmental Disabilities	41%
Behavioral Health Needs	22%

"There is absolutely no respite support for the medically fragile... It is extremely difficult to find individuals with the skill set needed to keep these individuals safe"

"Respite is critical for parents and family members who are supporting loved ones with moderate to severe disabilities."

Source: Final Performance Report

Source: Caregiver Survey

Respite Program Categories

Respite Innovation Categories

Number of Grantees in Each Respite Category
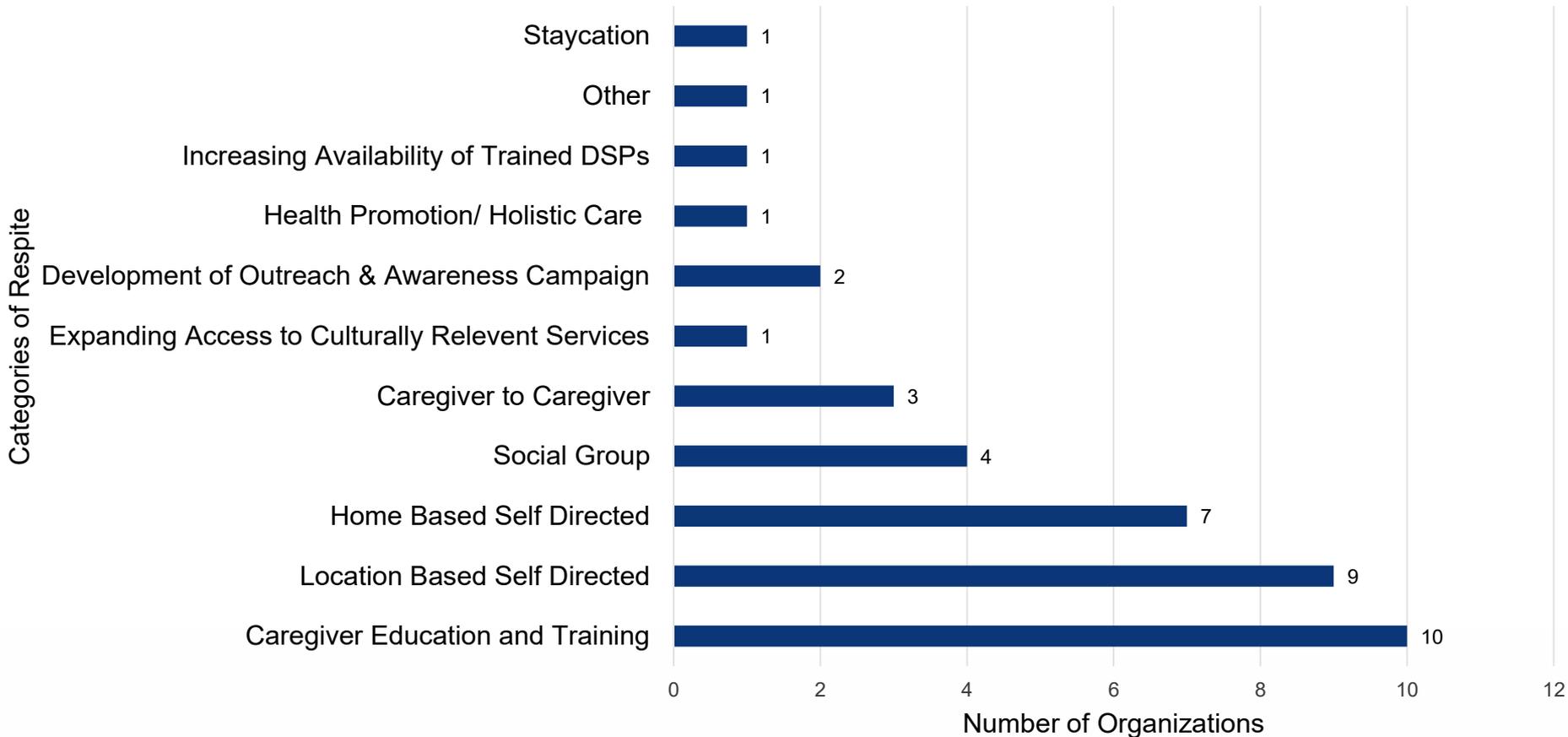
N = 40

Respite Categories

Caregiver Education & Training

Home-Based Self-Directed Respite

Location-Based Self-Directed Respite

Strategic Campaign Development for Awareness & Outreach

Expanding Access to Culturally Relevant Services

Increasing Availability of Trained Direct Support Professionals

Health Promotion/ Holistic Care

Social Group Respite

Staycation

Caregiver Education & Training - Factors For Success

- Provide information about definitions of respite and its benefits and how to access it

- Seek out trainers with lived experience as well as professional experience

- Provide outreach and training in multiple languages

Caregiver Training Topics

- Fostering empathy and stress management

- Managing anger and emotions

- Encouraging fun events for loved ones, leading to less stress for caregivers

- Building self-esteem and resilience for caregivers

> I feel stronger... I feel competent. I also feel like... my eyes were open to a lot of resources, I feel like my eyes were open to them before, but I didn't necessarily know how to connect to them and I think [staff] have been able to connect me... so I feel less isolated"
> -Caregiver Quote

Location Based Self-Directed – Factors for Success

Staffing/Logistics

- Provide weekend/evening respite hours to better meet caregiver needs

- Reliable and quality staff are important, be flexible with titles and responsibilities on the team

- Ensure consistent, transparent communication with caregivers, families, and staff

- Start planning and recruitment early to ensure readiness and recognize word-of-mouth communications

- Promote ongoing learning and best practices for staff including training for dementia care

Commitment to Caregivers

- Be patient and responsive to caregiver concerns and adapt using strategies such as:
    - Inviting natural supports (e.g., extended family, friends) to caregiver events
    - Connecting and partnering with local organizations

"My Young Adult always loves to go to the Respite Program when available. The care is top notch! I am able to do anything or absolutely nothing during the time she is there, without worrying about her."

Home Based Self-Directed – Factors for Success

- Focus on medical support needs when training, planning and recruiting

- Take the time to build trust with families

- Strong partnerships with community organizations is crucial to retainment

- It is important to have a variety of choices for respite options

"It allowed us to have care for my mother who needs help while I am at work. The cost associated with home care is extremely expensive and this grant gave us a wonderful gift by supporting that cost... None of us were aware of how important this service has been to our overall physical and mental health."

Social Groups – Factors for Success

Service Design & Experience

- In-person services are very impactful
- Social connection opportunities benefit both caregivers and care recipients and programs have found to have a positive impact on caregivers' well-being

Staffing & Project Management

- Reliable and high-quality staff are essential to successful group programming
- A strong project manager is critical for organizing and managing the program
- Caregivers prefer to choose their worker, when possible

Relationship Building

- Build rapport with families to create trust and engagement
- Be patient—relationships and trust take time

"The program does a wonderful job providing programs that allow caregivers to meet and share the day to day issues we all face. I look forward to each session and consider all the participants friends and know that I can call upon them any time I need help or guidance in dealing with an issue."

Caregiver to Caregiver – Factors for Success

- A dedicated Project Manager and reliable, high-quality staff.
- Prioritize building rapport with caregivers and families.
- Maintain transparent and consistent communication with caregivers and families.
- Collect and listen to participant feedback to improve services
- Identify cultural needs and incorporate them into programming
- Be malleable and adaptive in respite programming to meet diverse needs.

"Because of C2C I have gained a family for life. We share in quality family time together, provide respite both ways, friendship and kinship for both parents and children."

Lessons Learned

Barriers

Staffing Challenges
- Weekends
- Initial Hiring
- Nursing Staff

Caregiver Hesitancy

Common Barriers

Low Program Attendance
- Support groups
- Overnight Respite

Other
- Technology
- Cultural Barriers
- Infrastructure Challenges
- Public Awareness
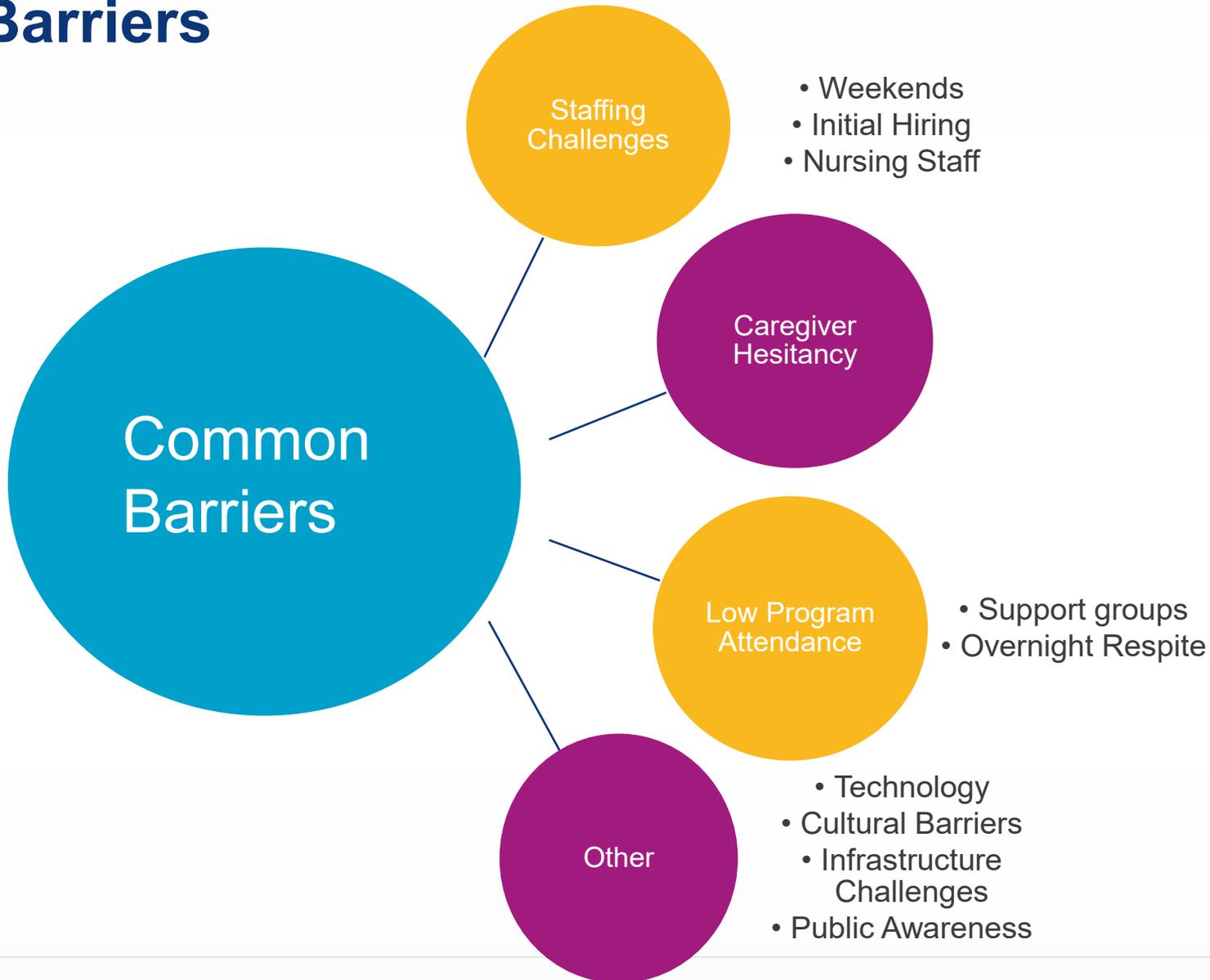
Lessons Learned

Collect and listen to participant feedback (13)

Have consistent, transparent communication with families, caregivers, and staff (9)

It is crucial to have reliable and quality staff (9)

Be malleable in respite programming (7)

Need to build rapport with families (7)

Most caregivers who had never before received respite were unaware that these services were available

Barriers to Receiving Respite

Legend:
- I did not know they were available
- Other
- I did not trust the providers
- Not needed
- Services were not offered
- Lack of transportation

Values in chart: 230, 21, 19, 18, 12, 4
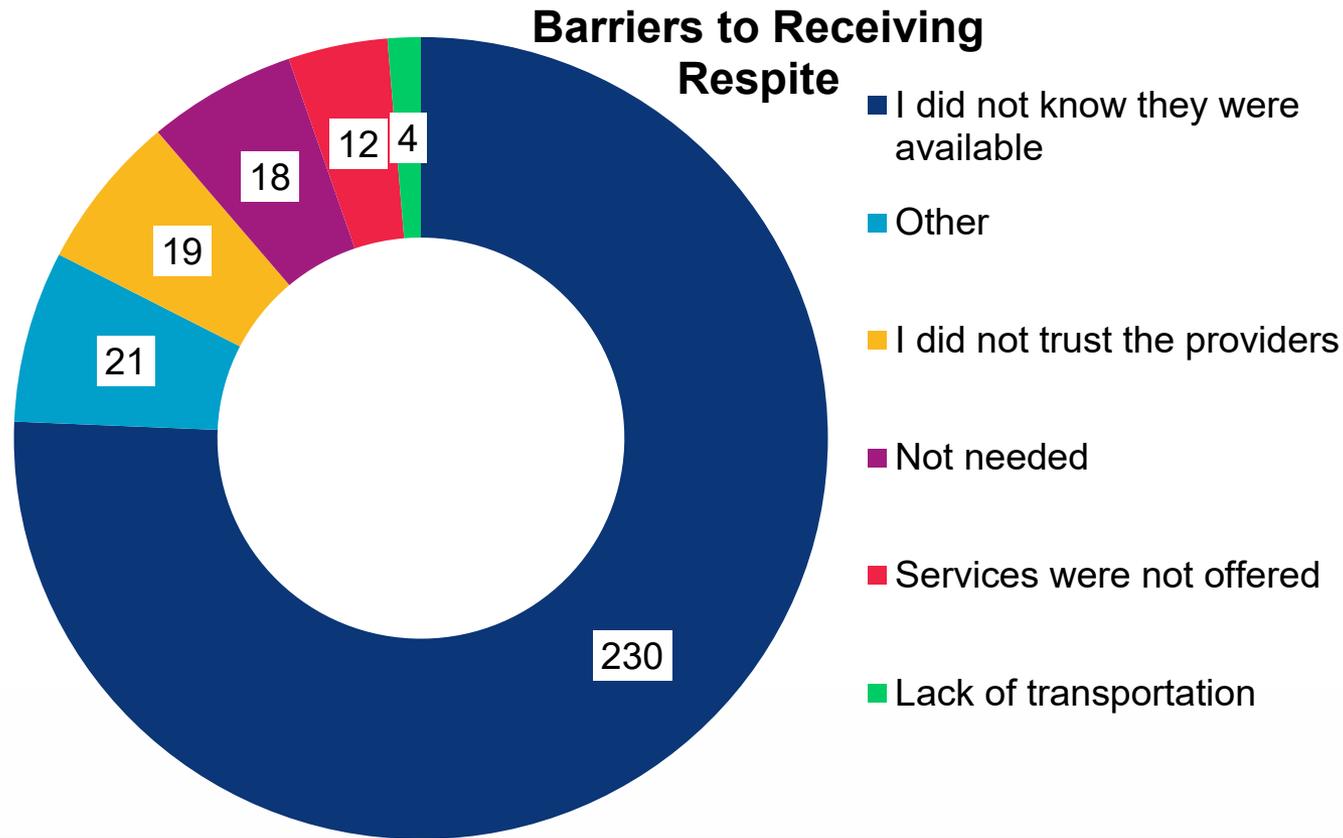
Average Weekly Respite Care Hours Reported by Caregivers Across Agencies

Actual Respite Hours vs **Desired** Respite Hours Received in a Typical Week

Legend: ■ Actual Avg Respite Hours Received ■ Desired Avg Respite Hours

Median Weekly Respite Care Hours Reported by Caregivers Across Agencies

Actual Respite Hours vs **Desired** Respite Hours Received in a Typical Week

Dumbbell chart showing Actual (dark blue) vs Desired (magenta) median weekly respite hours by agency:

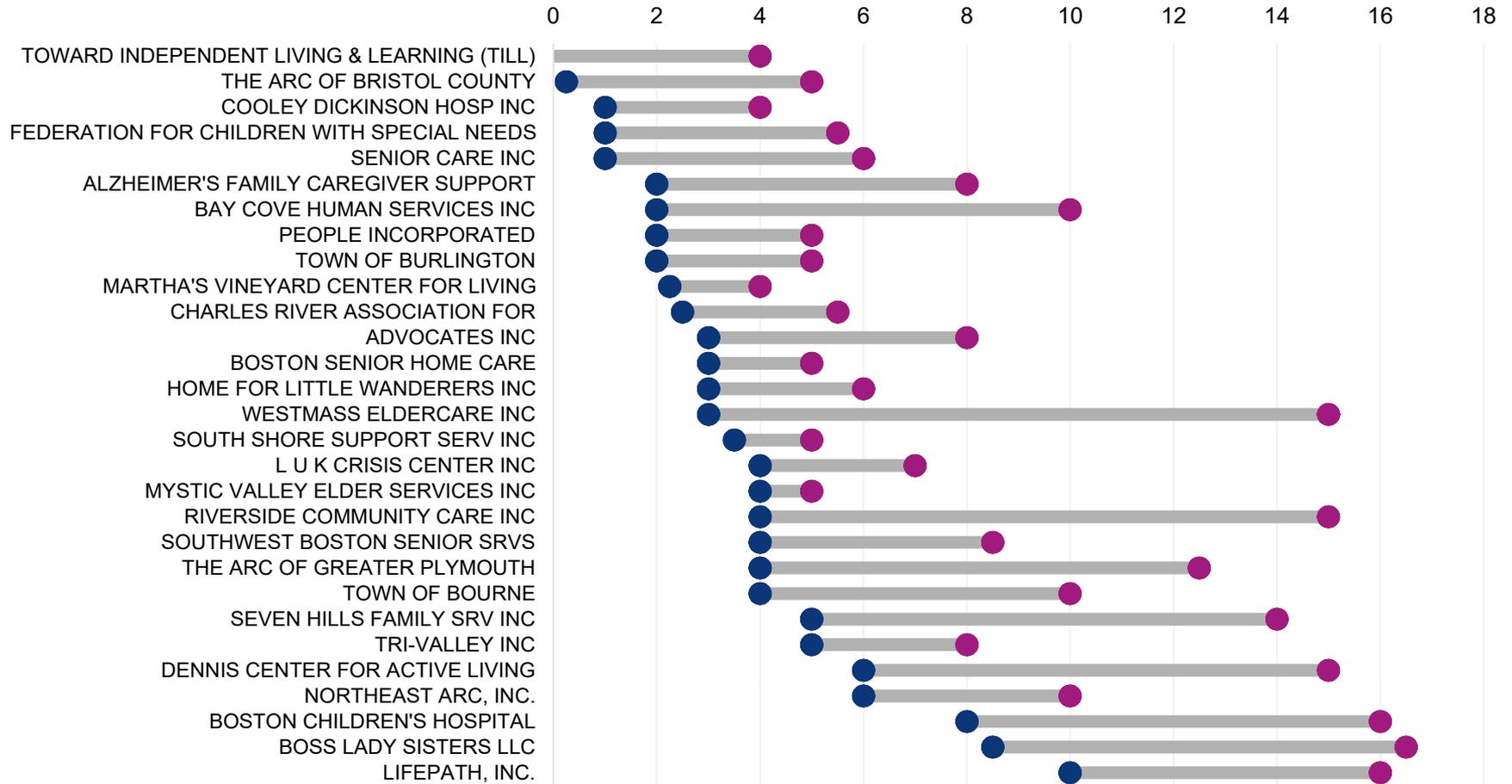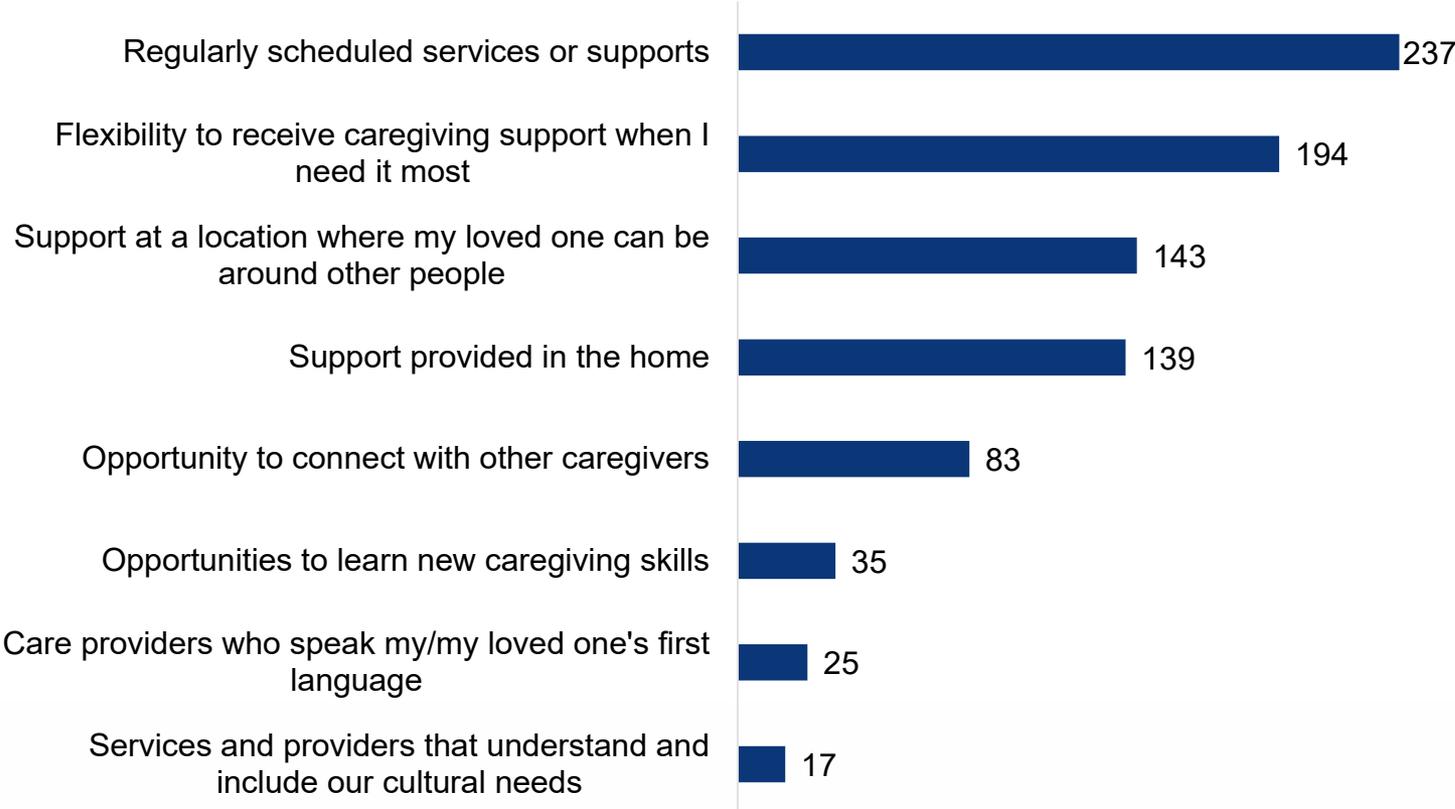| Agency	Actual	Desired
TOWARD INDEPENDENT LIVING & LEARNING (TILL)	0	4
THE ARC OF BRISTOL COUNTY	0.5	5
COOLEY DICKINSON HOSP INC	1	4
FEDERATION FOR CHILDREN WITH SPECIAL NEEDS	1	5.5
SENIOR CARE INC	1	6
ALZHEIMER'S FAMILY CAREGIVER SUPPORT	2	8
BAY COVE HUMAN SERVICES INC	2	10
PEOPLE INCORPORATED	2	5
TOWN OF BURLINGTON	2	5
MARTHA'S VINEYARD CENTER FOR LIVING	2.5	4
CHARLES RIVER ASSOCIATION FOR	3	5.5
ADVOCATES INC	3	8
BOSTON SENIOR HOME CARE	3	5
HOME FOR LITTLE WANDERERS INC	3	6
WESTMASS ELDERCARE INC	3	15
SOUTH SHORE SUPPORT SERV INC	3.5	5
L U K CRISIS CENTER INC	4	7
MYSTIC VALLEY ELDER SERVICES INC	4	5
RIVERSIDE COMMUNITY CARE INC	4	15
SOUTHWEST BOSTON SENIOR SRVS	4	8.5
THE ARC OF GREATER PLYMOUTH	4	13
TOWN OF BOURNE	4	10
SEVEN HILLS FAMILY SRV INC	5	14
TRI-VALLEY INC	5	8
DENNIS CENTER FOR ACTIVE LIVING	5.5	15
NORTHEAST ARC, INC.	6	10
BOSTON CHILDREN'S HOSPITAL	6.5	16
BOSS LADY SISTERS LLC	7	16.5
LIFEPATH, INC.	8	15.5

Overall Median Actual Hours: 4 Hrs
Overall Median Desired Hours: 9 Hrs

Requested Services

Caregivers were asked to select the top 3 needs they have for services and supports. This indicates the type of respite programing that would be most useful for caregivers.

Service	Count
Regularly scheduled services or supports	237
Flexibility to receive caregiving support when I need it most	194
Support at a location where my loved one can be around other people	143
Support provided in the home	139
Opportunity to connect with other caregivers	83
Opportunities to learn new caregiving skills	35
Care providers who speak my/my loved one's first language	25
Services and providers that understand and include our cultural needs	17

Respite Impact

Caregiving Impact on Employment

62% of caregivers needed to reduce work hours, change jobs or increase work flexibility due to their caregiving responsibilities.

Category	Percentage
Required additional flexibility in my job	32%
Required me to leave my job	15%
Required a reduction of hours	12%
Required me to change my job	3%
Other	8%
No impact	10%
N/A - I am not employed and was not employed when I started caregiving	20%
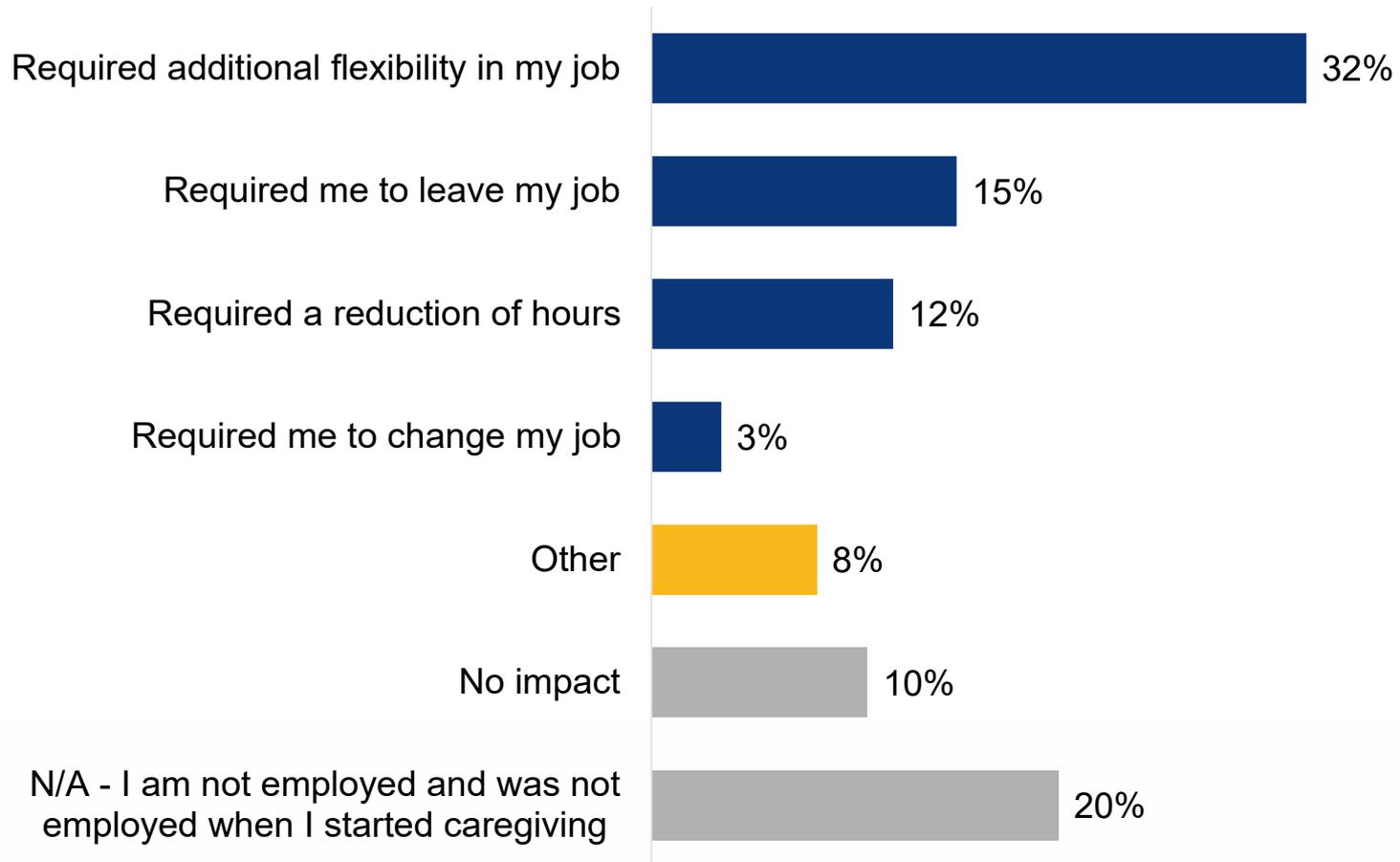
Benefits of Respite

Health and Well-being

Category	Value
Respite improves my mental health and well-being	83%
Respite improves my social health and well-being	58%
Respite improves my physical health and well-being	58%
Respite improves my spiritual health and well-being	33%
Respite improves my financial health and well-being	28%

Quality of Life

Category	Value
Respite improves the quality of life of the person I care for	69%
Respite improves my individual quality of life	68%
Respite improves the quality of life of my family	59%

Benefits of Respite

Relationships

Respite improves my relationship with the person I care for — **66%**

Respite improves my relationship with my spouse/partner — **49%**

Respite improves my relationship with my children — **36%**

Respite improves my relationship with my friends — **35%**

Respite improves my relationship with other family members — **34%**
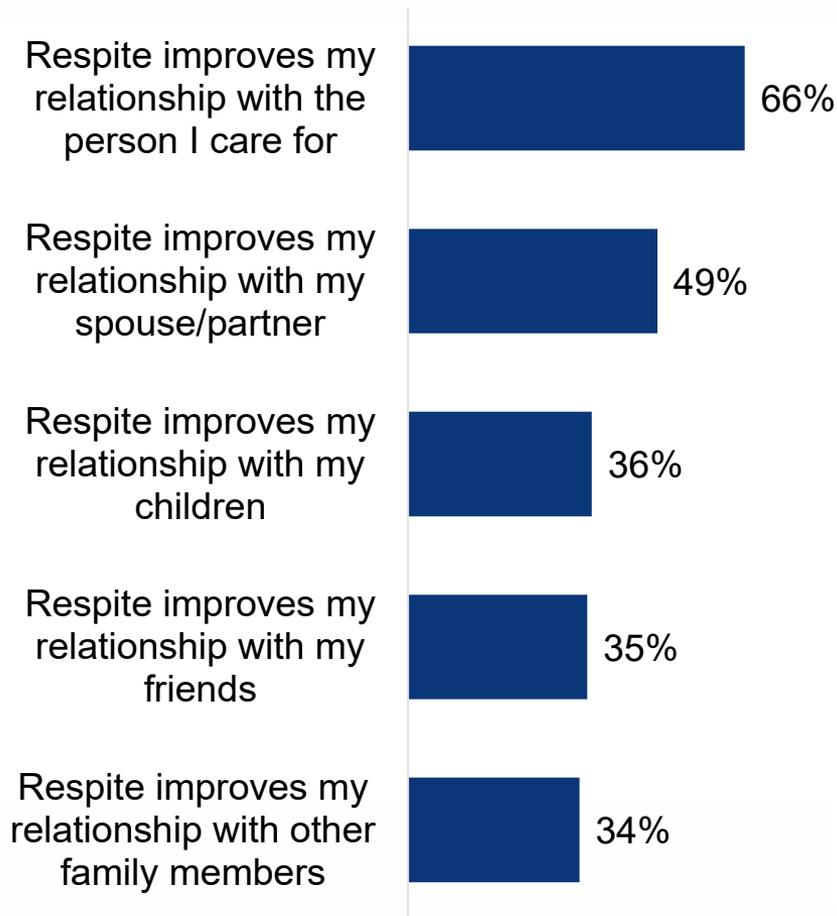
"I'm able to increase my work hours to provide financially for my family and decrease my financial worry."

"Caregiving is incredibly demanding and draining. I don't think I would be able to be as patient, generous, or kind if I didn't have respite. It is absolutely critical. "

"Time to myself."

Questions and Discussion