Lifespan Respite Care Program

Lifespan Respite Grantee Lead Agency: **Massachusetts Department of Developmental Services (DDS)**

**Funding Period:** September 1, 2018 to August 31, 2022

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**Primary Goal:** Increase the state’s capacity to serve individuals eligible for state agency services and the wider constituency who would benefit from respite.

### Key Performance Measures

The grantee identified the following four measurable objectives in support of their primary goal, and collected data according to those objectives.

1. Increased awareness by families on how to access respite services.
2. Increased number of qualified respite providers.
3. Shared strategies to develop and promote respite services across state agencies.
4. Track availability and utilization of respite provided by state agencies.

To measure cross agency collaboration (see: State and Community Partners and Notable Achievements), the grantee used the Levels of Organization Integration Rubric (LOIR) (Woodland, 2012).

### Notable Achievements

ForHealth Consulting (formerly Commonwealth Medicine), a division of the University of Massachusetts Chan School, served as training and evaluation coordinator during the grant period, supporting the lead agency’s efforts to support both access to respite provider training, and to respite services. In a study on state funded respite policies and programs, ForHealth Consulting identified the need to collaborate across state programs and agencies to improve respite access, improve tracking systems to measure respite service utilization, and to address workforce issues. These studies guided subsequent respite systems management and sustainability planning.

### Key Objectives, Activities and Outcomes

**Objective 1. Increase awareness by families on how to access respite services.**

**Notable Products and Performance Outcomes**

- The grantee developed a Family caregiver video as a vital tool to inform and support family members caring for a loved one. [https://youtu.be/MChah5Pqtns](https://youtu.be/MChah5Pqtns)

- The video was used to inform and support family caregivers in their caregiver roles, helping them to identify as caregivers, understand the benefits of respite, and access respite resources through MassOptions (free referral hotline) and Rewarding Work (respite referral directory).

- MassOptions offers a toll-free call center available to everyone regardless of income. Offering multiple languages, family caregivers can connect with a live person, Monday–Friday from 9a–5pm. MassOptions also offers a fully accessible, multi-lingual website (www.massoptions.org), so caregivers can search for services and supports any day or time. There is also an online chat option for caregivers who prefer text messaging.

### Coalition, ADRC and Community Partners

**State and Community Partners**

A strategic alliance, the State Action Group, worked to achieve and maintain a level of collaboration necessary to produce effective and sustainable change by aligning state respite program descriptions, identifying eligibility gaps, streamlining tracking, and accessing funding to support respite programs across the Commonwealth. State agency members of the State Action Group included program leads from the Executive Office of Health and Human Services, Department of Developmental Services (DDS), Department of Mental Health...
Objective 2: Increase number of qualified respite providers.

Notable Expansion Activities and Performance Outcomes

- To increase the pool of trained respite providers, an interagency respite training subcommittee was established and tasked with identifying and recommending a list of training core competencies. The final subcommittee recommended 12 core competencies to guide training of future, diversified groups of respite providers.
  - The competencies were shared with the ARCH Respite Work Group to inform the National Academy for State Health Policy (NASHP)/Respite Care Association of Wisconsin (RCAW)/ARCH provider training.
- Individuals seeking respite worker employment were provided access to free, quality, online training through Rewarding Work, Inc.
  - During the first quarter of 2022, a total of 39 people registered for the training, and eight (21%) completed the training.
  - Post training, individuals could post their availability on the Rewarding Work Directory.
  - Family caregivers were informed of the supply of respite workers and could post their need for respite services to the Rewarding Work Directory.

Objective 3: Share strategies to develop and promote respite services across state agencies.

Notable Partnerships and Expansion Activities

- Throughout the funding period, the MA Lifespan Respite Program (MLRP), comprised of the State Action Group, Commonwealth Medicine, a division of the University of Massachusetts Chan Medical School (CWM), and Rewarding Work, Inc., aimed to streamline access to respite and maximize opportunities to share information, resources, and lessons learned with the Massachusetts Aging Disability Consortia/No Wrong Door and the provider community. (Rewarding Work, Inc. conducts ongoing recruitment of respite workers, offers online respite training, and maintains the state’s Respite Directory.)
  - Through strategic planning led by the grantee and accomplished by the State Action Group, all state agencies are now included in the MassOptions NWD/ADRC referral system.
  - To provide fundamental knowledge to all state respite program services, the MLRP worked collaboratively with a ForHealth Consulting training development expert to develop a one-hour, online interagency respite training, the Massachusetts Family CARE: Helping Families Access Respite Essentials (MA CARE).
    - The MA Care online training is available to Massachusetts agency staff and other professionals working directly with families needing a break from the ongoing demands of caregiving.
    - In the final year of the grant, over 150 Options Counselors participated in a three-hour webinar that included the one-hour MA CARE Online Training, followed by interactive breakout sessions.
    - Access to the MA Care training is available on the MA Executive Office of Elder Affairs Learning Management System, www.biplearning.org. Training includes a downloadable catalogue of respite resources for professionals working with families in need of respite.
  - All state programs and community providers were informed of the Rewarding Work Directory and of national online respite training on the Rewarding Work website.

Coalition, ADRC and Community Partners

(DMH), Department of Public Health (DPH)/Children and Youth with Special Health Care Needs, the Executive Office of Elder Affairs (ELD), State Medicaid Program, and the Massachusetts Rehabilitation Commission (MRC).

State Respite Coalition/Organization Role
Key partners in this grant included all members of the MA Lifespan Respite Coalition; the State Action Group (made up of the Executive Office of Health and Human Services and the six human service agencies that provide respite – MRC, ELD, DDS, DMH, DPH, and MassHealth). Community partners included MA Council on Aging, Federation of Family Ties, Federation for Children with Special Needs, Senior Community Service Employment Program, Brain Injury Association, Thom Child and Family Services, Seven Hills, MassOptions, MA Society for the Protection of Cruelty to Children, Tri-valley Independent Living Center, Rewarding Work, Advocates, MA Home Care, and the MA Disability Council.

Aging and Disability Resource Center Role
The state’s ADRC/NWD, MassOptions program, was updated to include all state programs that provide aging and disability services, including respite. Family caregivers, regardless of income, have access to respite referrals through the MassOptions Program.
Objective 4: Track availability and utilization of respite provided by state agencies.

Notable Performance Measures

- The grantee sent an electronic survey to eight state program managers (members of the State Action Group). All programs (100%) responded providing the following baseline information on which strategic planning activities (see Objective 3) were based.
  - Baseline data indicated that although all regions of the state supported regional respite programs, 75% could not report readily accessible data about the number of families receiving state funded respite or the costs incurred.
- The grantee worked to reduce the risk of duplication of efforts and increase the promotion of existing programs by working with state agency leaders to conduct a SWOT analysis of the current state of the respite system, and to identify gaps and barriers existing in the system.
- Based on this assessment and collaborative planning, the grantee and partners implemented strategies to enhance and expand the current state respite referral and tracking system.
  - Through the MassOptions program, all state agencies are afforded access to ongoing respite referral data.
  - Enhancements to the MassOptions program allow the state to track:
    - Family caregivers’ demographics such as, gender, age range, and zip code;
    - Requests for respite by type (in-home, out-of-home, planned, emergency);
    - The date of the request and referral; and
    - The referral agency (state or community provider).

Program Flexibilities and Supports Introduced in Response to Covid-19

- The MLRP respite training pilot scheduled for 2020 at locally based community colleges was cancelled due to the pandemic. To address this challenge and keep this important initiative alive, the MLRP project director participated in an expert working group with the ARCH National Respite Network and Resource Center, and met regularly to provide input and expert consultation toward the development of a national online respite training.
  - Outcomes of the MLRP training subcommittee were shared with expert workgroup and a national online training was made available.
  - Massachusetts Rewarding Work volunteered to serve as a pilot site, promoting free online training for respite workers.