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Determination of Massachusetts' respite policies and the potential impact of unpaid family care giver support on home and community based services

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Determination of Massachusetts' Respite Policies and the Potential Impact of Unpaid Family Care Giver Support on Home and Community Based Services

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1. Introduction

Direct care workforce shortages, increasing health care costs, and limited access to services force many families to make life-changing decisions to care for family members with long term disabilities or who are chronically ill at home. In 2013, approximately 844,000 family caregivers in Massachusetts provided 786 million hours of care, with an estimated value of $11.6 billion.[i] Nationally, over 43 million family caregivers[ii] provide an estimated $470 billion worth of unpaid care annually.[iii]

While states strive to develop strategies to increase and sustain the direct care workforce, family caregivers continue to provide the necessary supports to keep their loved ones at home. To be successful, the future long-term care delivery system must be responsive to the increasing needs of the growing number of family caregivers. Respite, a short period of rest or relief for the family caregiver, is a key strategy to respond to the needs of families.

Understanding how a state program delivers respite services is a first step towards supporting the family caregiver and the valuable role they have in the state's long-term services and supports system. Studies show that respite reduces out-of-home placements,[iv] nursing home placements,[v] and hospitalizations,[vi] which can result in significant savings for public payers, such as Medicare and Medicaid, as well as private health insurance and personal out-of-pocket expenses.

For this project, the authors conducted an environmental scan of current policies and programs for state and federally funded respite services across Massachusetts' state agencies. Follow-up interviews with state program staff explored current delivery practices and potential gaps in Massachusetts' long-term services and supports (LTSS) respite programs and options. The results of this project demonstrate the variability in Massachusetts' state policies and program practices in four primary areas: 1) the types of respite services offered by state agencies, 2) the agencies definition of respite services, 3) variability in the ability of families to access services, and 4) the methods employed to track the delivery and outcomes of services. This study concludes with recommendations to enhance the delivery of respite as an integral part of long-term services and supports in Massachusetts.

2. Background

By 2030, more than a quarter of Massachusetts residents will be at least 60 years old, with many choosing to "age in place" in their homes.[vii] Life expectancy in Massachusetts exceeds the national average, with individuals 85 and older making up the fastest growing age cohort.[viii] The Massachusetts Medicaid program, known as MassHealth, offers a robust set of long-term services and supports. However, according to a 2014 nation-wide score card, Massachusetts ranks in the bottom quartile for family caregiver supports. [ix]

State agencies primarily provide support services that focus on the care recipient, rather than the needs of family caregivers. This is problematic because as the emotional and behaviorial challenges of the care recipient become more intensive, caregiver burden increases. To decrease the risk of caregiver burden and promote optimum health for the caregiver, family caregiver advocates highlight

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the need to view the caregiver and the care recipient as a single unit of care. They also urge policy makers to develop systems that collect family caregiver data, conduct appropriate needs assessments, and provide training and support for family caregivers.[x]

In 2014, the Massachusetts Lifespan Respite Coalition (MLRC)[1] conducted a needs assessment with family caregivers to identify the gaps in respite care for families in the commonwealth. Survey responses (n=380) highlighted three critical areas of need:

1. Access: more than one-third (36%) of families surveyed did not know where or how to access respite services.
2. Effect on employment: more than two-thirds (69%) of caregivers surveyed were employed. The impact of caregiving shows that nearly half (46%) were often late or needed to leave work early due to needs of their loved one; 41% used their vacation or personal time to provide care; 11% reduced their hours from full-time to part-time; and 27% had to change their career or position at work because of caregiver demands.
3. Financial burden: more than half (59%) of caregivers paid for respite services out-of-pocket, with annual costs that may have exceeded $5,000.

As the population in Massachusetts ages and individuals with disabilities live longer, states must stand ready to meet the growing needs of family caregivers. The MLRC needs assessment highlights that for caregivers to succeed in helping their loved ones to remain in their homes, accessible and flexible supports must be provided. [xi]

3. Methodology

A collaborative partnership at the University of Massachusetts Medical School (UMMS)/Commonwealth Medicine between the MassAHEC Network[2] and the Center for Health Law and Economics,[3] provided expertise for this study. A letter of support from the Secretary of Elder Affairs attested to the significance of the study from a state agency perspective (see: Appendix A).

An initial environmental scan of 28 state programs across 12 state agencies was conducted to determine the availability of publicly posted information about respite programs. The investigators then used a process evaluation approach and key informant interviews to assess existing state programs that receive public funding to support informal caregivers. Analysis of the environmental scan and gaps in information formed the questions for the key informant interviews (see: Appendix B).

3.1. Environmental Scan

The objective of the environmental scan was to develop a preliminary repository of respite programs and services in Massachusetts. Efforts included collecting agency specific definitions for respite, information about respite programs, funding sources and funding caps, program eligibility criteria, respite provider training requirements, and provider qualifications. Enhancement of the scan included a review of state budgets, state laws, state regulations, and state agency websites (see: Appendix C).

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[1] MA Lifespan Respite Coalition is funded by a grant with the federal Administration on Community Living and hosted by the MA Department of Developmental Services. The mission of the MLRC is to promote and support access to quality respite care options that enhance the lives of individuals and families with special needs throughout the lifespan.

2 MassAHEC Network is a program that strives to develop and grow a diverse, culturally responsive health care workforce. See: University of Massachusetts Medical School, Commonwealth Medicine, MassAHEC Network. Retrieved 02/06/2017, from: http://commed.umassmed.edu/topics-services/service/workforce-development

3 The Center for Health Law and Economics provides system-wide approaches to the design, development, and analysis of health care improvement efforts and purchasing strategies. See: University of Massachusetts Medical School, Commonwealth Medicine, Center for Health Law and Economics. Retrieved 02/06/2017, from: http://commed.umassmed.edu/centers-programs/center-health-law-and-economics

An outcome of the environmental scan revealed that information on respite programs was not readily available from a single source and gaps in information on respite services and programs remained after investigation. Table 1 lists the investigators' eight primary sources for respite with examples that suggest best practices for disseminating information to stakeholders.

Table 1 Respite Program Information Sources

Respite Source Type	Example
State agency websites	The MA Rehabilitation Commission Statewide Head Injury Program website clearly describes respite services, eligibility, and access.[xii]
State agency five year plans	The Executive Office of Elder Affairs' (EOEA) State Plan on Aging lists increasing access to respite services as a goal for upcoming years.[xiii]
State agency annual reports	The Department of Public Health (DPH), Annual Family Support for FY14 contains information and statistics about families receiving respite.[xiv]
State agency regulations	EOEA Home Care program provided the best example for defining respite, regulations, and co-payments for services.[xv]
State agency statutes	Very few statutes reference respite programs; however, the DPH Pediatric Palliative Care program does list respite as a service.[xvi]
State agency budget line items	State budget line items tend to refrain from listing respite. When respite is listed, it is offered as part of a broader program. Similarly, the financial information in the budget line-item is for the larger program.[xvii]
Publicly available Medicaid waivers or demonstration projects	The 1915c wavier, Money Follows the Person, describes the respite service specifically and outlines provider qualifications.[xviii]
Consumer facing state agency program guides	The Department of Social Services (now DCF), Guide for Foster and Pre-Adoptive Parents, clearly describes respite services, eligibility, and access. [xix]

3.2 Key Informant Interviews

The investigators interviewed managers from nine state programs identified as providers or potential providers of respite through a search of publicly available information. Table 2 lists the state agencies selected to participate in the key informant interviews.

The interview questions aimed to confirm the program definition of respite and to examine the implementation, operation, and tracking method of the state respite programs and ranged from 30 minutes to one hour. Two investigators attended each interview, one investigator recorded responses to interview questions, and a second investigator reviewed and edited the results. Investigators followed up with key informants on any outstanding questions and resource requests mentioned during the initial interview.

Table 2 Key Informant Interview – Participating State Agencies and Programs

State Agency	Program or Service Name	Description
Department of Developmental Services (DDS)	Family Supports	The majority of families access respite through individual flexible funding/stipend allocations administered through the Family Support Centers and other family support programs. This enables families of DDS eligible children and adults living at home with their families to identify and hire their own respite workers. With allocated funding, families can also choose to work with a qualified agency that provides them with a respite worker.[xx]
	Department of Elementary and Secondary Education – DDS Program	Intensive in-home program for children at risk of residential school placement. The primary focus of the program is on capacity and skill-building; however, some funds can be allocated for respite. The approach is usually the same as the one outlined above – families would identify and hire their own respite workers.
	Out-of-Home Respite	DDS contracts with a small number of planned respite homes within Massachusetts. One home in Western MA serves children and several others throughout the state serve adults. One of these is specifically for adults with complex medical needs. All of these homes are accessed via a referral from the DDS Area Office.
Department of Public Health (DPH)	Early Intervention – Regional Care Consultation (RCC) programs	A statewide integrated developmental service available to families of children ages 0-3 years with developmental delays and identified disabilities, or who are at risk for developmental delays. Respite program is coordinated through the six regional consultation programs.[xxi]
Executive Office of Elder Affairs (EOEA)	Home Care Program	Serves adults age 60 and over and individuals of all ages with a diagnosis of Alzheimer's Disease. Respite for family caregivers is determined by the consumer's functional impairment level and critical unmet needs.
	Family Caregiver Support Program	Supports family caregivers as they assist older relatives that are 60 years or older as well as grandparents and other relatives as caregivers who are 55 years or older with minor children and adults with disabilities by providing information, support, respite, and supplemental services.[xxii]
MA Rehabilitation Commission (MRC)	Statewide Head Injury Program (SHIP)	Offers supports for persons with externally caused brain injuries.[xxiii]
MassHealth Office of Long Term Services and Supports	Personal Care Attendant Program	Respite care is not covered for the caregiver as part of the personal care attendant program.[xxiv]
DMH	Division of Child, Youth, and Family Services (formerly Child and Adolescent Services)	Provides services to children or adolescents with serious emotional disturbance or mental illness through community services or residential level of care services including family therapy and family consultation.[xxv]

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During the key informant interviews, it was found that each state agency defined respite differently. The program definitions were influenced by access, availability, administration, and monitoring of program services. Table 3 describes the definition of respite by state agency and the recipients of respite services.

Table 3 Respite Definitions by State Agency in Massachusetts

State Agency	Respite Definition
DDS	Respite is a service that provides temporary relief for families and caregivers. Respite reduces family/caregiver stress and thereby helps preserve the family unit, supports family stability, and prevents lengthy and costly out-of-home placements.
DMH	Respite is short-term care of a child or youth with serious mental or behavioral health needs who lives at home. The purpose of respite is to give families a break from the exceptional caregiving demands related to that child and to support family health and wellbeing. Because caring for a child or youth with serious mental or behavioral health needs requires specialized knowledge, skills, and sometimes environment, respite services are not babysitting. DMH Respite is not a clinical service and is provided as part of an overall behavioral health treatment plan.
DPH	Respite provides temporary care to a child by anyone with childcare training or experience, such as another family member, friend, or a professional caregiver. Respite can occur in the home or in out-of-home settings for any length of time, depending on the needs of the family and available resources.[xxvi]
EOEA	Family Caregiver Support Program defines respite as temporary relief, at home, or in an adult day care or institutional setting, from their caregiving responsibilities.[xxvii]
	Home Care Program – the provision of one or more home care program services is to temporarily relieve the caregiver of a client in emergencies, or in planned circumstances, to relieve the caregiver of the daily stresses and demands of caring for a client in effort to strengthen or support the client's informal support system. In addition to services available under the Home Care Program, respite services may include short-term placements in adult foster care, nursing facilities, rest homes, or hospitals.
MRC	Respite is dependent on the different programs and their funding sources. Across programs, community respite providers must meet the same requirements as site-based providers. Services may be provided in family-like settings, licensed acute care settings, skilled nursing facilities, rest homes, assisted living residences, or by community respite providers as defined by waiver services definitions.
	Respite can provide Statewide Head Injury Program (SHIP) consumers or their caregivers with an opportunity for rest and relaxation or the opportunity to attend to their own personal needs. Respite services can be provided in or out of the home for limited periods of time, ranging from a few hours to one or two weeks.
MassHealth (Medicaid)	MassHealth does not cover respite as part of the state plan services.[xxviii]

Respite services are available through certain Home and Community Based Services (HCBS) Waivers that are administered by MassHealth and operated by state agency partners. The definition of respite varies by HCBS waiver programs, as shown in Table 4 found on page 6.

Table 4 Respite Definitions for HCBS Waiver Programs

HCBS Waiver Program	Respite Definition
Acquired Brain Injury Non-Residential Habilitation Waiver	Services provided to participants unable to care for themselves are furnished on a short-term basis because of the need for relief of family/informal caregiver, who normally provide care for the participant.
Acquired Brain Injury Residential Habilitation Waiver	Waiver services provided to participants unable to care for themselves are furnished on a short-term basis because of the need for relief of those persons who normally provide care for the participant.
Community Living, Intensive Supports, Adult Supports Waivers	Services are provided in either: a) licensed respite facility, b) in the home of the participant, c) in the family home, or d) in the home of an individual family provider to waiver participants who are unable to care for themselves.
Frail Elder Waiver, Traumatic Brain Injury Waiver & Money Follows the Person Community Living Waiver	Waiver services provided to participants unable to care for themselves are furnished on a short-term basis because of the need for relief of those persons who normally provide care for the participant.
Children's Autism Spectrum Disorder Waiver	Services provided to participants unable to care for themselves are furnished on a short-term basis because of the need for relief of family/informal caregivers who normally provide care for the participant.

4. Results

The results of the interviews highlight the need for consistent approaches between state agencies to obtain respite services, as well as monitor and report how respite is utilized. Training requirements for respite providers vary the least between state agencies because most programs do not have a standardized training requirement.

4.1 Eligibility and Access

Access points for respite services and programs vary across state agencies. While many programs screen individuals for respite needs during intake and assessment, other programs allow individuals and families to request respite care or services at regular intervals or after an individual's care needs change.

Youth who are authorized by DMH to receive one or more DMH community-based services, or who receive certain DMH residential services, may be authorized to receive DMH Respite Services if it is part of their treatment plan. This can include youth receiving MassHealth Intensive Care Coordination who have been authorized for DMH services through the DMH Service Integration Specialist (SIS). Youth receiving other MassHealth Children's Behavioral Health Initiative (CBHI) services who seek DMH Respite Services must go through the DMH Clinical Service Authorization process.

DMH provides respite for DMH authorized youth in the context of an overall treatment plan. Only in a very rare circumstance would DMH authorize respite as a stand-alone service; that is, the youth and the family are not receiving any other behavioral health services from any other provider.

Families receiving services from MRC may request respite at any time. However, for families with guardianship, a court order must be granted before respite can be accessed. DDS and the DPH Early Intervention (EI) program staff assume the responsibility of referring families for respite. DDS Service Coordinators can refer DDS eligible families to DDS Family Support Centers. DDS Area Offices allocate flexible funding to families, which can be used for respite. Funding is subject to

appropriation and may vary from one fiscal year to the next. DDS works closely with its network of Family Support Centers to support families in accessing respite supports as needed and available. Similarly, families receiving services from DPH EI are referred for respite by the EI Regional Consultation Program (RCP).

EOEA assesses the functional impairment level and critical unmet needs of the client at intake. A caregiver assessment determines the level of support needed for the family caregiver. EOEA clients access services through referrals from groups like the home health care, Councils on Aging, hospital discharge planning, or through direct contact with Aging Service Access Points. Family caregivers have access to limited respite through the EOEA Family Caregiver Support Program. Eligibility for services is available to caregivers whose loved one is age 60 and older, or has been diagnosed with Alzheimer's Disease or related dementia at any age.[xxix]

4.2 Training

Respite provider training and provider qualifications varied across programs. Most state agencies do not have a standardized respite provider training or training requirements. When training is needed for the worker, the family member typically trains the respite provider on their family member's needs. Families do not receive support for training. Additionally, across most programs, family members are not funded to serve as respite providers; rather, caregivers need to access qualified providers that are approved by the agency.

4.3 Tracking and Monitoring

State programs use different methods to track and report the utilization and provision of respite.

DDS Family Support Centers submit semi-annual data to DDS which includes the total dollar amount of flexible funding/stipend allocations, as well as the number of families who received an allocation. The amount of funding used for respite is not tracked separately.

DMH tracks service utilization through invoicing from providers under DMH programs. Reporting includes utilization based on the requirements of the program, such as the amount and percentage of flexible funds (i.e., individualized funds) used based on need.

DPH Regional Consultation Program staff track high-level data such as expenditures of family support and number of families served in that region. Respite is not tracked as a single service; rather, aggregate family support totals are reported to the state.

EOEA tracks and monitors information through the Senior Information Management System (SIMS), a web-based system of record for the home and community based care. The database includes individual care plans, assessment results, service authorizations, and payments. In addition, the federal Administration for Community Living tracks additional measures such as, expenditures, client data, provider data, staffing, and caregiver characteristics, and respite utilization.

MRC tracks service utilization provided through their SHIP and waiver programs; respite is included within the service package and not tracked exclusively.

MassHealth tracks utilization of services for MassHealth members and out-of-home placements through claims submission.

5. Challenges and Barriers

Common themes arose across state agencies regarding the administration and provision of respite services. Three primary challenges include inconsistent definitions of respite, limited ability to track respite utilization and expenditures, and limited caseworker and consumer awareness of respite

services across the delivery system. The investigators conclude this report with clear objectives to address the challenges identified.

As identified in Table 3, each state agency that offers respite defines the service differently. These varied definitions can cause confusion for state agency staff, family caregivers, and individuals who may receive support and services from multiple agencies. Inconsistent definitions of respite also create challenges in comprehensively tracking statewide utilization of respite services. The use of non-respite services to provide respite-like benefits also creates tracking issues, because the service used is not respite, but the service's purpose includes respite for caregivers. Tracking difficulties hinder the opportunity to provide a comprehensive view of respite availability, utilization and expenditures across the commonwealth. An additional challenge involves the lack of a mechanism to extract respite service delivery from the state agency's systems with individual level data for tracking and monitoring purposes.

Key informant interviews also noted that consumer awareness of respite services varied greatly across programs and agencies. Depending on the program, often limited public information is available about the service and family members may not know of the availability of respite services.. EOEA and DMH offer information to family members at intake or through brochures; however, this information may not be available after initial assessment, and these agencies share limited information online.

Knowledge of respite does not guarantee access to the service, particularly with families served by DMH. For example, the availability of out-of-home respite for DMH families is limited by the number of beds available for respite purposes through DMH contracts. MRC clients also experience limited availability of out-of-home respite sites and qualified providers. This concern has additional challenges for guardians of MRC consumers, given that guardians must obtain court approval prior to accessing respite services.

Some state agencies do not publicize materials for consumers describing respite due to eligibility limits. DDS and DPH program staff assesses families' needs for respite and recommend the service to families based on those needs. The challenge with this model is respite becomes reactive rather than proactive. In addition, staff must be aware of how to assess a family for respite so the service can be offered on a timely basis. Furthermore, key informants were unsure if information pertaining to eligibility, access, and administration of respite services were included in the programs' on-boarding process for staff.

Because of the challenges in tracking the provision and outcomes of respite, state agencies often cannot determine whether respite, if offered routinely as part of an individual's care plan, would reduce or prevent out-of-home placements. Key informants noted that some individuals and families are ineligible for respite, and noted the need information on alternative supports for ineligible individuals and families who seek respite.

6. Discussion

Families carry a heavy burden as they provide the majority of long-term care to their loved one.[xxx] An MLRC report showed that over 50% of caregivers provided more than 40 hours of care per week, with most caregivers being 50 years or older.[xxxi] More than half (58%) of caregivers pay for respite to ensure their loved ones receive the care needed to keep them at home.[xxxii] The 2016 reauthorization of the Older Americans Act provides funding for the caregiver allotment administered through the National Family Caregiver Support Program. [xxxiii] In Massachusetts, this benefits programs that serve older adults, such as those administered by EOEA in collaboration with the area agencies on aging.[xxxiv]

The study methodology assessed available program policies and public facing materials for some of Massachusetts' respite programs. Addressing three primary challenges: inconsistent definitions,

limited tracking methods, and decreased awareness of respite services, will likely improve spending, access and utilization of respite across state programs.

Utilizing the same definition across programs would increase the state's ability to accurately track the utilization of respite services statewide. To assess the efficacy of respite care and services available in Massachusetts, improved tracking of respite utilization and spending are needed. In addition, future research studies should assess the value of respite services on improving health outcomes for the caregiver and the care recipient. Increasing awareness of respite programs through public facing materials, websites, and media outlets will increase the family caregiver's understanding of the value of respite, as well increase the utilization of respite across the long-term care continuum.

7. Recommendations

The following recommendations come directly from the interviews with state agency staff and the analysis of information about respite programs in Massachusetts. Many of these recommendations could be implemented with limited resources; others may require a more significant investment.

Promote consistency of respite service across state agencies

- Convene a meeting of state agency staff responsible for respite to review commonalities and differences across agencies
- Develop a consistent definition of respite services and care across state agencies, including agency-specific eligibility criteria
- Develop a state respite plan that standardizes state agency definition of respite and defines best practices
- Orient staff to policies and procedures for accessing and delivering respite to family caregivers and care recipients
- Collaborate across agencies to develop lists of qualified direct care agencies that can provide state, federal or privately funded respite

Increase awareness of and access to respite services

- Increase awareness of respite services through MassOptions[xxxv] website and call center
- Develop cross agency respite training across Massachusetts state agencies, including eligibility and target population, to enhance awareness of and access to respite programs
- Promote the respite provider registry[xxxvi] to increase access to respite providers
- Create more public facing documents describing respite services, eligibility, and how individuals can request respite

Increase the number of qualified respite providers

- Promote access to free online training for respite volunteers as well as formal and informal providers

Track availability and utilization of respite provided by state agencies

- Develop measures of respite service availability, utilization, expenditures and outcomes
- Request annual reports on respite services from state programs that provide respite
- Summarize the impact of respite services provided across state agencies and across the commonwealth

8. Conclusions

Family caregivers ensure that the most vulnerable are able to remain at home. A recent (2014) article reports, "*the cost of family caregiving for aging family members in the United States is estimated to be $522 billion a year*."[xxxvii] For Massachusetts, understanding the existing infrastructure and delivery of respite care and services and relieving caregiver burden is a crucial first step in reducing out-of-home placements of elders and individuals with disabilities. Additional research and a more integrated approach across state agencies will inform policy development, state programs, and fiscal operations on the potential health care savings and improved health outcomes for both the caregiver and the care recipient.

Appendix A Letter of Support

dThe Commonwealth of Massachusetts
Executive Office of Elder Affairs
One Ashburton Place, 5th Floor
Boston, Massachusetts 02108

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September 10, 2015

Leanne Winchester, MS RN
Project Director for Workforce Development
University of Massachusetts Medical School
CWM/CHPR MassAHEC Network
333 South St
Shrewsbury, MA 01545

Dear Leanne,

The Massachusetts Executive Office of Elder Affairs is pleased to support your proposal to the Commonwealth Medicine FY 2016 Internal Grant Program to analyze current state policies to better understand the existing practices for supporting home and community based services, specifically respite.

The vision of the Executive Office of Elder Affairs is to ensure that elders in Massachusetts have the supports necessary to maintain their well-being and dignity. We aim to promote the independence and well-being of elders and people needing medical and social supportive services by providing advocacy, leadership, and management expertise to maintain a continuum of services responsive to the needs of our constituents, their families, and caregivers.

I look forward to collaborating with you and the University of Massachusetts Medical School to assess the outcomes of this project.

Sincerely,

Alice Bonner
Secretary

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Appendix B Key Informant Interview Questions

Program Overview

- How do you/your program define respite provided through [insert agency name]?
- Who are the recipients of respite in your program?
- Are there programs beyond those listed below that provide respite services to families your agency services? [insert list of respite programs found]
- Is any other information available on the program that we have not yet found? [provide list of reports/brochures relevant to agency]. We're especially interested in:
    - Agency Strategic Plans
    - Provider Manuals
    - Operational protocols for case worker/managers
    - Agency budget or spending plans

Funding Information

- How is respite funded within your program (state or federal funds)?
- How much funding supports respite annually?
- Is there a maximum dollar amount available for respite within a specified timeframe?

Eligibility

- How is eligibility for respite determined?
- When can someone, in the program, access respite?

Tracking information

- What system(s) do you/your program use for tracking access?
- How do you/your program monitor this information?
- How often is this information updated?

Access/Barriers

- How do family members and guardians learn about respite services available through your program/agency?
- What are the common barriers family members connected with your agencies experiences in accessing family caregiver or respite services? (Examples from ARCH Respite presentation)
    - Limited fiscal resources to sustain or expand programs
    - Affordability
    - Too few trained providers or respite options
    - Reluctance to ask for help or self-identify as caregivers
    - Multiple and siloed funding streams with confusing and restrictive eligibility criteria, waiting lists

Quality/Training

- Are there any training requirements for respite workers that provide services through your agency's programs?
    - If so, what training is utilized?
    - Who provides the training?
    - How frequently and where is the training provided?
    - What qualifications are necessary for those that provide respite within your program?

Closing

- Do you have any resources that you recommend we refer to for information about respite? Is this a publicly available document?
- Is there anyone else you would suggest speaking with about your agency's respite programs?
    - If yes, do you have contact information for that person?

Resources to Request of State Agency Contacts

- Provider Manuals
- Looking for any agency requirements to become a respite provider (or certification/licensure requirements)
- Agency Strategic Plans
- To see how respite fits in to the agency's goals, and how the agency plans to use respite services in the near future
- Operational Protocols for assessor's/case managers
- To determine when need for respite is assessed (is it only assessed once or is it assessed regularly)
- To get more information about respite eligibility guidelines for assessors
- Agency budget or spending plans
- To get more detailed information re: FY spending for respite

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Statutes, Budget Line Items, and Regulations Referencing Respite Care

Appendix C State Resources

Respite Statutes

Agency	Citation	Language
Department of Public Health—Boston Health Care for the Homeless Program Respite	MGL ch. 111 §24J	"There is hereby established a program of medical respite services provided by the Boston health care for the homeless program. Said program shall be administered by the department, subject to appropriation. Any revenues generated by said program shall be credited to the General Fund."
Department of Public Health—Pediatric Palliative Care Program	MGL ch. 111 §24K	Pediatric Palliative Care Program: "Services provided by the program shall be determined by the department and shall include, but not be limited to…respite services, provided by professional or volunteer staff under professional supervision."
Division of Medical Assistance (ie: MassHealth)—PCA Workforce Council	MGL ch. 118E §72	PCA Workforce Council Duties: "…Provide routine, emergency and respite referrals of personal care attendants to consumers and consumer surrogates who are authorized to receive long-term, in-home personal care services through a personal care attendant."
DESE—Special Education Services	MGL ch. 71B §12A, 12C	"Habilitative services, services directed toward the alleviation of limitations on major life activities of a disabled person, including… respite care" "A disabled person who has been receiving special education under the provisions of this chapter shall be eligible, subject to appropriation, upon graduation from high school or upon attaining the age of twenty-two, whichever occurs first, to receive habilitative services in the manner hereinafter provided…"

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Agency	Citation	Language
Massachusetts College Student Loan Authority	MGL ch. 15C §29	ABLE Accounts: "Achieving a better life experience account or ABLE account, a savings and qualified disabilities expense account established and maintained by the authority, or a designated administrator, pursuant to this section and its implementing regulations for the purposes of qualified disability expenses."

Respite Related Budget Line-Items

Agency	Line Item Number	Language
MassHealth-AFC	4000-0600	"MassHealth shall maintain the same respite benefits for adult foster caregivers that were in affect January 1, 2015"
Massachusetts Rehabilitation Commission	4120-6000	"For services for individuals with head injuries; provided, that notwithstanding any general or special law to the contrary, the commission shall establish a pilot community center to be located in Worcester county by June 30, 2016 $15,817,983" (Respite services are covered under this line item, although not referenced specifically)"
Department of Public Health	4513-1020	"that funds from this item shall be expended to provide respite services to families of children enrolled in early intervention programs who have complex care requirements, multiple disabilities and extensive medical and health needs; provided further, that priority shall be given to low- and moderate-income families; provided further, that the department shall submit to the house and senate committees on ways and means a report on the number of families served by the program and the amount of funds appropriated in this item granted to qualified families not later than January 8, 2016"

Agency	Line Item Number	Language
Department of Public Health	4590-1503	"For the pediatric palliative care program established in section 24K of chapter 111 of the General Laws $1,800,000"
Department of Children and Families	4800-0038	"For guardianship, foster care, adoption, family preservation and kinship services provided by the department of children and families; provided, that services funded through this item shall include…respite care services"
Department of Developmental Services	5920-3000	"For respite services and intensive family supports" $55,933,705
Department of Developmental Services **Executive Office of Elder Affairs-Home Care Program**	5947-0012 9110-1630	"For the purposes of a federally funded grant entitled, Lifespan Respite Care Program" $82,500 "For the operation of the elder home care program, including contracts with aging service access points or other qualified entities for the home care program, home care, health aides, home health and respite services"

Respite Regulations

Agency	Regulation	Language
Department of Children and Families	110 CMR 7.050	"Families with developmentally disabled children may be eligible to receive respite services from the Department of Mental Retardation, under the auspices of an Interagency Agreement between the Department and DMR. (This Interagency Agreement, as of July 1, 1988, transferred the responsibility for providing those respite care services for developmentally disable persons that were previously defined in 110 CMR 7.000, (specifically 7.050 through 7.057), to the Department of Mental Retardation.)"

Agency	Regulation	Language
Department of Children and Families	110 CMR 7.051	"The Department may develop and make available other forms of respite care for other populations of families and/or children served by the Department."
Department of Developmental Services	115 CMR 3.09	Respite Provider Requirement: "The head of every provider of residential, day, or site-based respite services ("provider" in 115 CMR 3.09) and every specialized home care placement agency subject to 115 CMR 5.00 shall establish and empower a human rights committee in accordance with the requirements of 115 CMR 3.09."
Department of Developmental Services	115 CMR 7.02	Respite Definition: "Family Supports. Refers to those supports and services which are provided at home on an intermittent or ongoing basis to enable the family to stay together and to be welcomed, contributing members of their home communities. These include, but are not limited to the following: (a) Respite Supports. Refers to family supports provided or purchased by the Department for the purpose of increasing or maintaining the capacity of the individual to remain in his or her own home. Such respite supports include the following types of supports: (b) Family Respite. Refers to respite supports provided in the home of the individual by a person recruited, supervised, and paid by the family. (c) Home-based Respite. Refers to respite supports provided by any person who is recruited, trained, supervised, and paid by a placement agency for the purpose of providing respite care either in the provider's home or

Agency	Regulation	Language
		in the home of the individual. (d) Site-based Respite. Refers to any respite supports provided by a provider in a location that is not the home of the individual or of a provider who resides in the home."
Department of Developmental Services	115 CMR 7.03-7.08	Requirements for respite providers including: outcomes for individuals, site capacity, site staffing, environmental requirements and safety requirements.
Department of Developmental Services	115 CMR 7.09	Additional Standards for Respite Supports: "In addition to the requirements of 115 CMR 7.01 through 7.08, all providers of respite supports shall: minimize upset and disruption of the individual's typical life patterns and enable participation in life routines in accordance with the individual's ISP; obtain a thorough knowledge of each individual's medical needs, including his or her ability to communicate health and medication needs; and take necessary actions to assist the individual in the transition between home and provider, where feasible and when requested by the individual, family, or other primary care provider."
Department of Developmental Services—Licensure and Certification Requirements	115 CMR 8.01	The Department shall license and/or certify: (a) Licensure. All public and private providers offering…site-based respite…must be licensed, excluding those that are subject to licensure by another governmental agency with which there is written agreement between the Department and such agency for licensure exclusion. (b) Certification. All public and private providers offering…site-based respite… are subject to

Agency	Regulation	Language
		review of outcomes, in addition to those required for licensure that the Department determines are consistent with standards published in 115 CMR, excluding those that are subject to licensure or certification by another governmental agency with which there is written agreement between the Department and such agency for certification exclusion…"
Department of Developmental Services—Licensure and Certification Requirements	115 CMR 8.10(1)	"Approval for Occupancy is required for any home where 24-hour staffing is provided and where the home is owned, rented or leased by the provider; in all locations where work/day services are provided; and in locations where ***site-based respite*** services are provided."
Division of Medical Assistance (ie: MassHealth)—Home Health Program Regulations	130 CMR 403.402	Respite Definition: "a range of services provided on a short-term or intermittent basis in response to the need for relief of those persons who normally provide this care."
Division of Medical Assistance (ie: MassHealth)—Home Health Program Regulations	130 CMR 403.410(c)	"Home health services are not to be used for homemaker, respite, or heavy cleaning or household repair."
Division of Medical Assistance (ie: MassHealth)—Home Health Program Regulations	130 CMR 403.421(c)	"The MassHealth agency does not pay for homemaker, respite, or chore services provided to any MassHealth member."
Division of Medical Assistance (ie: MassHealth)—PCA Program Regulations	130 CMR 422.12(A)	"MassHealth does not cover any of the following as part of the PCA program or the transitional living program: (A) social services, including, but not limited to, babysitting, respite care…"
Division of Medical Assistance (ie: MassHealth)—Hospice Benefit Regulations	130 CMR 437.423(H)	"Short-term Inpatient Care. (1) Facilities. Short-term general inpatient care for pain control and symptom management and ***inpatient respite care*** must be provided in a facility that meets the criteria specified in 42 CFR 418.108.

Agency	Regulation	Language
		(2) Limitations. During the 12-month period beginning November 1st of each year and ending October 31st of the following year, the aggregate number of inpatient days (for both general inpatient care and ***inpatient respite care***) may not exceed 20% of the aggregate number of days of hospice services provided to all MassHealth members during that same period."
Division of Medical Assistance (ie: MassHealth)—Hospice Benefit Regulations	130 CMR 437.424(A)(3)	"Inpatient Respite Care. The inpatient respite care rate is paid for each day the member is in an approved inpatient facility and is receiving respite care from the hospice. Payment for inpatient respite care will be made for a maximum of five consecutive days' stay including the date of admission but not counting the date of discharge. Payment for any subsequent days will be made at the routine home care rate."
Division of Medical Assistance (ie: MassHealth)—Hospice Benefit Regulations	130 CMR 437.424(B)(1)	"The MassHealth agency does not pay a hospice the room and board per diem amount, and does not pay for medical-leave-of-absence days, for any day that a member receives inpatient respite care (130 CMR 437.424(A)(3)) or general inpatient care (130 CMR 437.424(A)(4)) from the hospice."
Division of Medical Assistance (ie: MassHealth)-Early Intervention Services Regulations	130 CMR 440.413	"The Division does not pay early intervention programs for the following: (A) research or experimental treatment; (B) educational services; (C) recreational services; (D) nutritional counselling; ***(E) respite services;*** (F) home- or center-based visits not conducted by a nurse, an occupational therapist, a

Agency	Regulation	Language
		physical therapist, a speech and language pathologist, a social worker, or a psychologist; and (G) any visits, screenings, group sessions, or assessments that are missed by a member or cancelled."
Division of Medical Assistance (ie: MassHealth)—HCBS Waiver Regulations (ABI waivers and MFP waivers)	130 CMR 630.402	Respite Definition: "services provided to individuals unable to care for themselves; furnished on a short-term basis because of the absence or need for relief of unpaid caregivers."
Division of Medical Assistance (ie: MassHealth)—HCBS Waiver Regulations	130 CMR 630.404(D)(16)	Requirements to be a respite provider: "In order to participate as a provider of respite services under an HCBS waiver, a respite provider must be: (a) licensed as a hospital by the Massachusetts Department of Public Health under 105 CMR 130.00: Hospital Licensure; (b) certified as an assisted living residence by the Executive Office of Elder Affairs under 651 CMR 12.00: Certification Procedures and Standards for Assisted Living Residences; (c) licensed as a nursing facility by the Massachusetts Department of Public Health under 105 CMR 153.00: Licensure Procedure and Suitability Requirements for Long Term Care Facilities; (d) able to meet site-based respite requirements established by the Massachusetts Department of Developmental Services under 115 CMR 7.00: Standards for All Services and Supports; (e) licensed as a respite care facility by the Department of Developmental Services under 115 CMR 7.00: Standards for All Services and Supports; (f) licensed as a rest home by the Massachusetts Department of Public Health

Agency	Regulation	Language
		under 105 CMR 153.000: Licensure Procedure and Suitability Requirements for Long Term Care Facilities; or (g) enrolled in MassHealth as a participating adult foster care provider under 130 CMR 408.000: Adult Foster Care."
Division of Medical Assistance (ie: MassHealth)—HCBS Waiver Regulations	130 CMR 630.405(B)(3)	Acquired Brain Injury Non-Residential Habilitation (ABI-N) Waiver Services: "The following ABI waiver services are covered for eligible MassHealth members who are enrolled as participants under the ABI-N Waiver… (3) respite"
Division of Medical Assistance (ie: MassHealth)—HCBS Waiver Regulations	130 CMR 630.405(D)(16)	Money Follows the Person Community Living (MFP-CL) Waiver Services: "The following HCBS waiver services are covered for eligible MassHealth members who are enrolled as participants under the MFP-CL Waiver:…(16) respite."
Division of Medical Assistance (ie: MassHealth)—HCBS Waiver Regulations	130 CMR 630.407(A)	"Limitations on Covered Services…With the exception of ***respite services***, as described in 130 CMR 630.425, and transitional assistance, as described in 130 CMR 630.433, the MassHealth agency does not pay for HCBS waiver services provided to a participant who is a resident or inpatient of a hospital, nursing facility, intermediate care facility for the mentally retarded, or any other medical facility subject to state licensure or certification."
Division of Medical Assistance (ie: MassHealth)—HCBS Waiver Regulations	130 CMR 630.408(C)	"(3)The MassHealth agency does not pay an HCBS waiver provider for…any service to a person who is a resident or inpatient of a hospital, nursing facility, intermediate care facility for the mentally retarded, or any other medical facility subject to state licensure or certification, except for ***respite services***, in accordance with 130 CMR

Agency	Regulation	Language
		630.425, and transitional assistance, in accordance with 130 CMR 630.433" "(5) the cost of room and board, unless provided as part of ***respite care*** in accordance with 130 CMR 630.425"
Division of Medical Assistance (ie: MassHealth)—HCBS Waiver Regulations	130 CMR 630.425	"(A) Conditions of Payment. Respite care is covered solely to provide temporary relief to non-paid caregivers when the participant requires assistance with activities related to independent living. (B) Nonpayable Services. (1) Respite care is not covered for the purpose of compensating relief or substitute staff for a paid service provider. (2) Respite care is not covered for any time period during which other assistance with activities related to independent living is available to a participant."
Executive Office of Elder Affairs-Home Care Program	651 CMR 3.01	Respite Definition: "The provision of one or more Home Care Program services to temporarily relieve the caregiver of a Client in emergencies, or in planned circumstances, to relieve the caregiver of the daily stresses and demands of caring for a Client in efforts to strengthen or support the Client's informal support system. In addition to services available under the Home Care Program, Respite Care services may include short term placements in Adult Foster Care, Nursing Facilities, Rest Homes, or Hospitals."
Executive Office of Elder Affairs-Home Care Program	651 CMR 3.03(2)	Home Care Eligibility: "Age. An individual must be age 60 or older. Individuals under the age of 60 with a physician's documented diagnosis of Alzheimer's Disease who meet the eligibility criteria set forth in

Agency	Regulation	Language
		651 CMR 3.03(3), (4) and (5) are eligible to receive Respite Care Services."
Executive Office of Elder Affairs-Home Care Program	651 CMR 3.03(3)(g)	"Respite Care Services may be provided under the Home Care Program to Caregivers in accordance with the Voluntary Copayment Schedule and Home Care Program Cost Sharing Schedule set forth in 651 CMR 3.03(3)(e)3 and 3.03(3)(f) and in accordance with the provisions set forth in 651 CMR 3.03(3)(e), (f) and (g). The annual gross income used to determine the Respite Copayment is based on the sum of the annual gross income of the Respite Client and his/her spouse. If a Client is in need of and eligible for Respite Care, and is over the financial eligibility income categories set forth in 651 CMR 3.03(3)(e) and (f), the following Respite Care Copayment Schedule shall be used. (1) Over-income Cost Sharing for Respite Care. The monthly Co-payment for Respite Services for Over-income clients shall be determined by multiplying the cost of Respite Services by the applicable percentage listed in the Over Income Cost Sharing For Respite schedule set forth in the Financial Eligibility Guidelines in effect during his/her initial determination or redetermination of financial eligibility as defined in 651 CMR 3.03(3)(j)."
Executive Office of Elder Affairs-Home Care Program	651 CMR 3.03(5)(a), (b)	"(a)Long Term Care Assessment for Home Care Program Services. After determining that the Applicant or Client has a FIL of one through four, the ASAP shall determine the extent of need for Home Care Program Services. The assessment shall also

Agency	Regulation	Language
		determine a Caregiver's need for Respite Services." "(b)Clients whose Caregivers are in need of Respite Services shall be categorized under the appropriate FIL and shall be determined to have one or more Critical Unmet Needs."
Executive Office of Elder Affairs-Home Care Program	651 CMR 3.03(6)(b)	"Service Plan. After determining an Applicant's eligibility pursuant to 651 CMR 3.03(2), (3), (4), and (5), if the ASAP determines that the Applicant or Client is in need of Home Care Program Services or the caregiver is in need of Respite Care services, a service plan will be developed."
Executive Office of Elder Affairs-Elder Protective Services Program	651 CMR 5.14	Elder Protective Services Program Plan may include Respite services.

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