



Massachusetts Lifespan Respite Coalition
Respite Environmental Scan/Needs Assessment Document
August 2014

The Massachusetts Lifespan Respite Coalition (MLRC) was formed in September 2010 with support from a Lifespan Respite grant from the U.S. Administration for Community Living (ACL), in order to improve quality of life for family caregivers of people of all ages and disabilities. In subsequent years, the MLRC has received two additional grants from ACL which have allowed it to continue and expand upon its work. All of these grants are hosted by the Massachusetts Department of Developmental Services (DDS).

The 2010 grant called for the MLRC to accomplish several key tasks, including the completion of a written assessment on the state of respite services in Massachusetts. To that end, we embarked on a series of information gathering activities in 2011 and 2012. With the assistance of the Massachusetts Executive Office of Elder Affairs (EOEA), we developed a Family Caregiver Respite Service Needs Survey which was distributed widely across the state, both electronically and in paper form. We also conducted a series of Key Informant Interviews and Focus Groups with professionals and family caregivers representing a range of disabilities and age groups. In addition, we benefitted from the work of an intern at EOEA who developed a detailed table describing the respite programs offered within Massachusetts' state agencies.

The MLRC Family Caregiver Respite Survey consisted of some demographic information, 14 questions, and room for additional comments. The survey was first released in September-October 2011 and then reactivated from January – April 2012. A total of 380 responses were received.

The majority of caregivers who responded identified as white (93%), female (87%), between 45-64 years of age (64%), married or living with a partner(76%), employed full time or part time (57%), and caring for only one care recipient (85%).

The care recipients range in age from <18 years of age (27%), 18-59 years of age (34%), and >60 years of age (39%). They cope with a range of conditions, most predominantly long term/chronic health and medical conditions; cognitive impairment other than dementia and Alzheimer's Disease, intellectual and

developmental disabilities (including Autism Spectrum disorder), and dementia and Alzheimer's Disease. The relationship between caregiver and care recipient ranges from parent (47%), children (24%) and spouse (21%). Over 50% of care recipients required more than 40 hours per week of care.

Some of the most striking findings from survey included the following:

- Although 84% of respondents stated that having respite enabled them to care for their loved one(s), only 33% indicated that the amount of respite services they received were meeting their needs.
- 69% of respondents would prefer respite to be provided in-home rather than in an out-of-home setting. 25% stated that they are seeking out-of-home respite.
- 59% of respondents felt that finding a person or agency that is able to meet the specific needs of their loved one is the most important consideration when seeking respite services. This was by far the highest rated consideration. The other options were that respite services be affordable (23% rated this as most important), that respite be available when needed (18% rated as most important), and that respite services be easily accessible (2% rated as most important).
- The majority of caregivers (58%) paid for respite care with out of pocket personal expenditures. 50% had annual out of pocket respite expenditures of \$1,500 or more.
- Of the 57% of respondents who are employed either full or part time, 58% said their caregiving responsibilities have caused them to arrive late or leave work early. 54% have had to miss work days due to caregiving. 59% have used their vacation or other personal time to provide care.

Written comments included in the survey highlighted several other themes:

- Survey respondents included numerous comments related to the **lack of easily available information on respite and how confusing it is to navigate the system:**

"State help takes forever!!!!!!! And that is not acceptable for a family with a member with primary progressive MS."

"Hard to find help; lots of confusing paperwork."

"I need respite care but have no idea how to apply/obtain/qualify."

"...I have yet to have respite given to our family on a regular basis. It seems like it is a secret until you find an organization that offers it and then you have a hard time receiving it on a regular basis. This is so aggravating that sometimes I do not even attempt to seek it out."

"It would be of benefit if all the services and information could be in one "location"/phone call/easy access...The caregiver, and family, should not have to track down the information and do the research. Trust me...they are already researching and gathering files of information on Alzheimer's, the disease, and anything they can find online, or in person!"

"A respite service database would be helpful along with materials/presentations that can help reluctant caregivers and/or care recipients become more acquainted and accepting of service possibilities."

- Respondents also provided numerous comments about **the difficulty in finding a qualified respite provider, even if financial support is available:**

"Willing to pay out of pocket, but could not find qualified provider."

"Recently received funding, but can't find qualified provider."

"We work with a state agency which has funding for respite care, but no vendors."

"Finding a caring, responsible person whom we can trust, and who is realistic about availability/consistency, has been a real challenge."

"We just lost another respite care worker. Caregiver turnover is ongoing. It's really tough to hang on to people. It'll probably take us a few months to find someone again. That burden usually falls on me (the mom), and I just don't have that much time."

"It is very difficult to find respite workers that are both qualified and trustworthy to handle complex medical conditions and cognitive impairment."

- Additionally, several poignant comments were provided about **the critical importance of having small, predictable amounts of respite care:**

"I think if I were able to get respite care one or two times a year, I would be able to keep caring for my mom longer in my home. To feel that there is no break to look forward to makes it hard to carry on."

“When he was 12, we put our son in a residential treatment program. His behavior was dangerous and explosive...if we had had even a little routine, predictable respite, we might have been able to avoid getting to the place where our recourse was having him live somewhere else.”

“Respite and support are essential from the beginning and should not be delayed until the state feels a residential placement is imminent.”

“My husband and I are more than happy to care for our son 99% of the time but need an occasional alone time to nurture our marriage because we are never alone.”

“We (were) only getting \$500 a year, not very much. But just enough to get a couple of weekend breaks. That’s all we really needed. I find it hard to believe that that was going to break the bank.”

“Respite is essential for families in Massachusetts. While some may think it is simply an excuse for a free night out, what they don’t understand and cannot fathom is the stress that accompanies caring for a lover one who is disabled whether mentally or physically...Respite is not a frivolous request. It is a survival technique.”

The findings from the MLRC survey were mirrored closely by the findings from two additional caregiver surveys administered around the same time, one by DDS and the other by the Massachusetts Department of Mental Health (DMH). **The DDS Family Supports Survey** was open from November – December 2011. Of the respondents to this survey, 61% said they had limited their job choice to care for their family member with a disability. 41% of respondents said they had incurred between \$500 - \$2000 in out-of-pocket expenses related to the care of their family member over the past year, with 39% of them reporting out of pocket expenses specifically related to respite care. 48% indicated that they needed respite, but that these supports were not available. When asked “What family supports are most important to you?”, by far the most frequently mentioned item was Respite. (84 responses compared to 36 each for the three next most frequently mentioned items, Recreation/Social/Life Skills; Personal Care Attendants, and Financial Assistance). **The DMH Survey** was developed jointly by DMH and the Parent/Professional Advocacy League (PPAL), a statewide family advocacy organization for families of children with severe emotional disturbance. This survey was available from June-July 2012. Among respondents to the DMH survey, only 18% stated that they are currently accessing respite care. 32% said they found out about respite through word of mouth from other parents. Close to 25% of respondents were unsure if they’d ever gotten helpful information about respite. 64% indicated that the greatest barrier to receiving respite was that they couldn’t find anyone to provide respite care. The MLRC finding that many families valued small, predictable amounts of respite care was reinforced by the DMH survey finding that 40.9%

of the parents of children identified as having very serious needs said that only 1-2 times per week was the right amount of respite care.

The Key Informant Interviews were conducted by MLRC staff using a standard set of questions and interview prompts. Questions focused on several main themes, including the need for respite in each population; how respite is paid for; barriers to respite; advocacy/community projects/creative ideas in each population; and where families find providers. A total of 12 Interviews were conducted during February and March of 2012, representing the following populations:

Person/Title	Agency	Population Represented
<ul style="list-style-type: none"> • Kerri Ikenberry, RN, BSN; Associate Director of Care Management 	<ul style="list-style-type: none"> • Community Case Management: UMass Medical School – Commonwealth Medicine Division/ • MassHealth (MA Office of Medicaid) 	<ul style="list-style-type: none"> • Children and young adults under age 22 with complex medical needs (requiring more than 2 hours per day of skilled nursing)
<ul style="list-style-type: none"> • Joseph Kelley; Metro South Regional Coordinator – Brain Injury and Statewide Specialized Community Services 	<ul style="list-style-type: none"> • Massachusetts Rehabilitation Commission – Statewide Head Injury Program (SHIP) 	<ul style="list-style-type: none"> • People (of any age) with externally caused traumatic brain injury and associated impairments in behavioral, cognitive and/or physical functioning.
<ul style="list-style-type: none"> • Christine Cannon, Director of Family Supports • Mary Roach, President (interviewed together) 	<ul style="list-style-type: none"> • United Cerebral Palsy of Metro Boston • Neuro-Rehab Management, Inc. 	<ul style="list-style-type: none"> • People with cerebral palsy, neurological impairments, brain injury, multiple sclerosis
<ul style="list-style-type: none"> • Leslie May-Chibani • Debbie Dowd-Foley; Caregiver Specialists – Statewide Family Caregiver Support Program 	<ul style="list-style-type: none"> • BayPath Elder Services/ • Elder Services of Worcester, Inc. 	<ul style="list-style-type: none"> • Family caregivers of adults age 60 or older or people with Alzheimer’s disease of any age • People age 55 or older raising a grandchild, young relative or caring for a disabled

(interviewed together)		person
<ul style="list-style-type: none"> • Margaret Van Gelder, Director of Family Support 	<ul style="list-style-type: none"> • MA Department of Developmental Services 	<ul style="list-style-type: none"> • Children with Developmental Disabilities and Adults with Intellectual Disability
Person/Title	Agency	Population Represented
<ul style="list-style-type: none"> • Debra Freed, Executive Director 	<ul style="list-style-type: none"> • Paralyzed Veterans of America, New England Chapter 	<ul style="list-style-type: none"> • Veterans with spinal cord injury
<ul style="list-style-type: none"> • Karen Baker, LICSW, New England Regional Social Worker 	<ul style="list-style-type: none"> • Huntington’s Disease Society of America 	<ul style="list-style-type: none"> • People with Huntington’s Disease
<ul style="list-style-type: none"> • Sue Loring, Director 	<ul style="list-style-type: none"> • Autism Resource Center of Central Massachusetts 	<ul style="list-style-type: none"> • Children and young adults with autism spectrum disorders
<ul style="list-style-type: none"> • David Chevalier, Children’s Service Coordinator 	<ul style="list-style-type: none"> • MA Department of Developmental Services, Central-West Regional Office 	<ul style="list-style-type: none"> • Children with developmental disabilities in rural parts of Western Massachusetts
<ul style="list-style-type: none"> • Jan Obermann, Care Coordinator 	<ul style="list-style-type: none"> • ALS Association – Massachusetts Chapter 	<ul style="list-style-type: none"> • People with ALS
<ul style="list-style-type: none"> • Focus Group of Families 	<ul style="list-style-type: none"> • National Multiple Sclerosis Society – Greater New England Chapter 	<ul style="list-style-type: none"> • People with multiple sclerosis
<ul style="list-style-type: none"> • Gloria Castillo, Co-Director 	<ul style="list-style-type: none"> • Autism Support Center – Northeast Region 	<ul style="list-style-type: none"> • Children and young adults with autism spectrum disorders, including Hispanic families

Findings in each thematic area are summarized below. Full notes from each interview, as well as some key demographic information gleaned from the interviews, are included in the Appendices.

NEED FOR RESPITE:

- Family caregiver may be caring for multiple care recipients (aging parent and own children) and working. The leads to no down time for family caregiver.

- The experience of a family caregiver caring for someone with dementia can be “similar to combat soldiers” – the unpredictable behavior of the care recipient leads to increased stress levels in the caregiver. Respite for this caregiver is critical.
- Emergency Respite options are very limited or non-existent. What happens when the caregiver gets sick?
- Grandparents raising grandchildren need respite.
- Single parents – need afterschool, evening, weekend, overnight respite.
- Veterans often have a waiting period for respite of one year or more – services depend on eligibility factors and nature of medical condition or injury (service related or non-service related).
- Everything revolves around the child with a disability in a family unit. Siblings suffer. Respite allows for typical time with other children in the family.
- Families are looking for opportunities to do typical things (go out to dinner, away for weekend, go to a wedding) – respite allows for that.
- Skilled nursing/provider needed for care recipients with complex medical issues who require 24 hour care – family caregiver needs a break.
- Out of home respite for TBI population is basically non-existent, therefore not an option.
- Aging caregivers often have their own health issues.
- Unsafe situations can arise then caregivers have to leave individual at home alone to run errands or to work, and there is no one to care for individual.
- Caregivers don’t get to sleep.
- PCA hours are often the only form of in home staff available, but this is not really respite.
- Family members continue to provide care until they can’t any more, and this can become an emergency situation.

HOW SERVICES ARE PAID FOR:

- Some individuals qualify for some respite funding, but dollar amounts are often insufficient.
- Many Caregivers pay out of pocket to supplement any funding.
- Agency funding can vary year to year depending on budget.
- Veterans depends on formula used to determine level of need, eligibility, pre or post 9-11 veteran, service or non-service related injury or condition – each situation is individually evaluated and determination made.

- Occasionally small amounts of funding from Private foundations/organizations are available.
- For a small amount of people, long term care insurance can cover some respite.
- Accident victims (TBI) sometime cover respite using settlement funds.
- For some people with adult onset and other disabilities, it's worth looking to see if they are eligible for Veterans benefits or Elder Services.

BARRIERS TO RESPITE:

- Caregivers often not able to self-identify. They are caring for own child, parent, spouse, and do not see themselves as a caregiver or someone who needs respite. There is a feeling of guilt and isolation.
- Caregivers are living in the moment and not looking at the future – they don't know what chronic caregiving is like and do not realize how respite will factor in.
- Caregivers often unable to find a respite worker trained in particular skills needed for care recipient's special needs (challenging behavior, medical issues, etc.) There is often a lack of trust in provider.
- In rural areas, it's difficult to find respite workers to travel far for a few hours of work. If using local workers, there are often privacy issues. Not as many providers listed on directories west of Route 495 (Central and Western MA). Families have limited resources and often lack transportation.
- Not enough sites/respite homes or centers for medically challenged individuals regardless of age or disability and existing ones are very expensive or have waiting lists to get in.
- Non-English speaking families may need training on how to use respite funding because they haven't had it before and don't self-identify as a caregiver.
- Individuals with adult onset issues (ALS, MS, etc) are "miserable" in skilled nursing facilities where population is elderly, often with dementia, and not socially compatible with younger adults with medical needs.
- Some families do not want to be identified as having a disability (ex. of people with Huntington's) – emotional issues difficult for family members to deal with.
- Less costly to the family to keep medically complex children in pediatric nursing home than in community – expensive services provided for direct care – respite would be additional cost at home.
- We often see families with income too high to qualify for assistance, but who can't afford out of pocket expenses for respite provider and other things.

INNOVATIVE IDEAS/COMMUNITY PROJECTS/ADVOCACY:

- Concept of ongoing regular respite to address caregiver's basic needs, seeing respite as part of healthy caregiving practices.
- Time banks are an option for low cost or free respite using the barter system.
- Important to have flexibility with how funds are used and choices for families. Every family is different and care recipient's needs are different.
- Arrangement with nursing homes to notify agency (ALS) when bed may be available for short term – agency notifies family who can take advantage of short term respite and pay daily rate out of pocket and also needs to hire nursing assistance as well.
- Use of more community resources and collaboration among community resources and family cooperatives.

WHERE FAMILIES FIND PROVIDERS:

- Community agencies or programs contracting with funding sources that care recipient may be eligible for.
- Teacher's aides/school or program staff from individual's program.
- Families setting up own network with other families, community, etc.
- College students, Rewarding Work, Care.com, Craig's List, family members, friends – Family responsible to do own background check.

Another piece of information gathering consisted of a detailed **Table of Respite Programs within Massachusetts' State Programs**, compiled between October – December 2012 by Emily Worm, an intern at the MA Executive Office of Elder Affairs. This table outlined the types of respite offered by most of the State Health and Human Services Agencies in Massachusetts. This chart is significant in several ways. First of all, Ms. Worm stated that it was very challenging to gather the information, due in large part to the fragmentation of the system and the fact that respite supports were often embedded within larger funding streams. Secondly, several agencies reported wait lists of varying duration for respite supports, while others reported that they were able to provide respite to all who requested it. And finally, several programs noted that there have been extreme variations in funding levels over the past five years. In two cases, programs were cut entirely and then partially reinstated when the economy began to improve.

These findings of fragmentation and confusing information are reinforced by a **recent report completed by UMass Medical School – Commonwealth Medicine**. The May 2014 report, entitled “Balancing Incentive Program (BIP) Structural Requirement Review,” was completed in order to gather background information related to three major structural changes required by BIP. Although this task is much broader and all-encompassing than respite alone, there are still lessons to be learned for the MLRC contained within this report. In particular, the report looked at how Massachusetts is doing with implementing a true “No Wrong Door (NWD)” system. If a NWD system were truly operational, individuals and families from across the state would be able to access the same type of information regardless of where they live, which would include designated entry points/agencies, an informative website, and an 1-800 number that would connect individuals with NWD agencies.

The UMass report found that Massachusetts has partially met the requirement for a NWD system through their ADRC network, but that better and more comprehensive information needs to be made available to the ADRC’s. This is certainly true of respite services. The report also found that for the most part, state agencies do not meet the criteria of being NWD agencies as they all serve very defined populations, and those who do not meet eligibility are unable to access information from these agencies.

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