

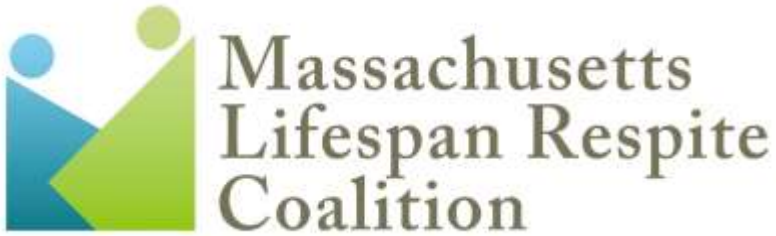


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Lifespan Respite
Coalition

Measuring Impact: Evaluation Lessons from Massachusetts Lifespan Respite Coalition Programs

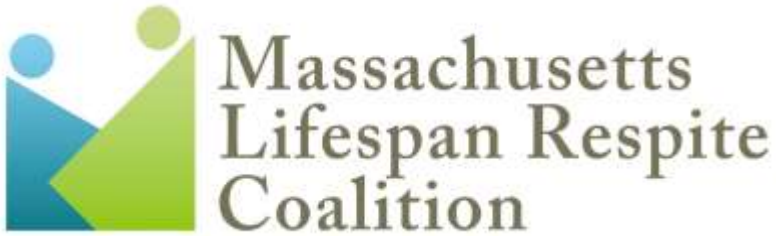
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The Massachusetts Lifespan Respite Program

- ▶ Funded by ACL since September 2010
- ▶ DDS is lead agency
- ▶ Collaborative project with EOHHS and Executive Office of Elder Affairs
- ▶ Active, committed Coalition - 500+ people on distribution list
- ▶ Broad representation across disability groups, non-profit and state agencies, and caregivers



The Massachusetts Lifespan Respite Program

- ▶ Awarded Lifespan Respite Expansion Grant in 2012
 - Funding opportunity required that the majority of the funding be spent on direct provision of respite
 - Focus of our grant was the awarding of 10 \$10,000 Respite Innovation Mini-Grants



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Why Mini-Grants?

- ▶ Required minimal fiscal administration compared to vouchers or other similar approaches
- ▶ Allowed for a variety of tailored respite options
- ▶ Provided opportunity to compare a variety of respite models

Outcomes for Expansion Grant

- ▶ Decreased caregiver stress/improved caregiver quality of life
- ▶ Increased information on cost-effectiveness of various respite models
- ▶ Comparison of the effectiveness of various respite models
- ▶ Replicable model for distribution of respite funding

**That sounds great,
but how do we measure all that?**



- ▶ Through networking with MLRC members, invited several local academics to join time limited evaluation work group
- ▶ Using resources on ARCH website, did preliminary search of existing survey instruments
- ▶ Sent out questions in advance of evaluation group conference calls to make best use of limited time



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Evaluation Work Group - How it Helped

- ▶ Working with academics helped us to refine and clarify our thinking
- ▶ Emphasized the importance of using validated assessment tools whenever possible
- ▶ Helped us to define our:
 - OUTCOMES
 - VARIABLES
 - DATA ELEMENTS



OUTCOMES

- ▶ Information on cost-effectiveness of various models of respite service
- ▶ Positive respite experience for caregiver and care recipient

VARIABLES

- ▶ Number of individuals participating in each mini-grant
- ▶ Intensity of care recipient's need
- ▶ Differences in model of respite provision

DATA ELEMENTS

- ▶ Number of individuals/families served, number of service hours provided
- ▶ Demographic data about caregiver and care recipient
- ▶ Care recipient's level of care required
- ▶ Caregiver's level of perceived stress
- ▶ Caregiver satisfaction with respite services provided



Final Mini-Grant Evaluation Tools

- Perceived Stress Scale (PSS-14) with two questions added from the Lubben Social Network Scale.
 - <http://www.psy.cmu.edu/~scohen/globalmeas83.pdf>
 - <http://www.bc.edu/content/bc/schools/gssw/lubben/downloads/jcr%3acontent/content/download/file.res/LSNSR.pdf>
- Client Level of Care Determination Chart
 - <http://www.lifespanrespite.memberlodge.org/Resources/Documents/RC%202011%20Level%20of%20Care%20Determination%20Chart.pdf>
- Demographic Information Form
 - <http://www.lifespanrespite.memberlodge.org/Resources/Documents/Respite%20conference.2011%20PR1.pdf>
- Monthly Agency Tally Sheet (designed by MLRC)



Implementation Strategy – the Plan

- ▶ Mini-Grant funding was to be distributed in three payments:
 - First payment at outset of program
 - Second payment upon receipt of mid-year data
 - Third payment upon receipt of final mini-grantee report

- ▶ Kick-off Meeting held with all 10 grantees at outset of project:
 - Conducted training on evaluation tools
 - Discussed importance of the data and potential national implications

- ▶ MLRC designated a Mini-Grantee “point person”:
 - Was contact person for all questions about funding, programming, data collection, etc.
 - Conducted mid-year program visits to all 10 grantees



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Lessons from the Field

Summary takeaways from the Massachusetts Lifespan Respite Mini-Grant Evaluation's Findings

Program's Goals and Objectives

- To increase respite services
- To promote mutual awareness and collaborations among providers of respite and other community-based services
- To compare cost-effectiveness of multiple respite models

Desired Outcomes

- Decrease caregiver stress and improve caregiver quality of life
- Increase information on cost-effectiveness of various respite models
- Explore new models for sustainable respite care
- Increase collaboration among providers of respite, health, and social services
- Identify a replicable model for distribution of respite funding

Diverse Models

271 participants received 3,718 respite hours

Diverse Models: Types of Programs and Payments

- In-home respite
- Out-of-home respite
- In-community wellness, social and recreational activities
- Facility-based respite
- Vouchers and cash assistance with choice of options
- Membership and activity paid for by the program

Demonstrated Capacity to:

- Develop innovative strategies
- Expand sustainable collaborations
- Provide respite services

Targeted Populations:

- MS and other adult onset conditions
- Higher income (ineligible for gov't support)
- Cultural and linguistic minorities

Diverse Participants

271 participants; 145 provided demographic data

- Of these 145 – majority are white, highly educated, married, caring for a family member, own their home, income > \$60,000
- Care recipients: average age is 55; near even gender split
 - 28% cared for by parents
 - 38% cared for by spouses
 - 11% cared for by adult children

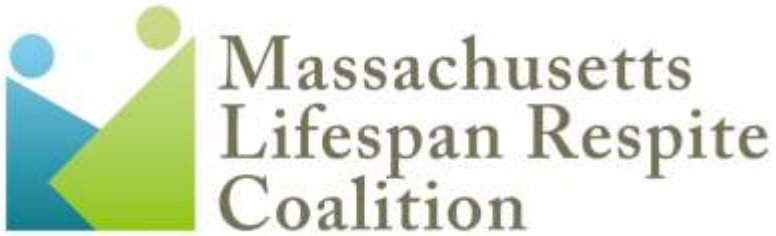
Care Needs

- ▶ Alzheimer's and Other Related Dementia (41%)
- ▶ Multiple Sclerosis (26%)
- ▶ Other Needs (26%)
- ▶ Developmental, mental or other types of health issues (7%)

- ▶ Level of Care
 - Level 1: Mild: requires monitoring, supervision, and assistance within age-appropriate range (28%)
 - Level 2: Moderate: requires same support as Level 1 but greater level (49%)
 - Level 3: Severe: constant or near constant monitoring, supervision and assistance (23%)

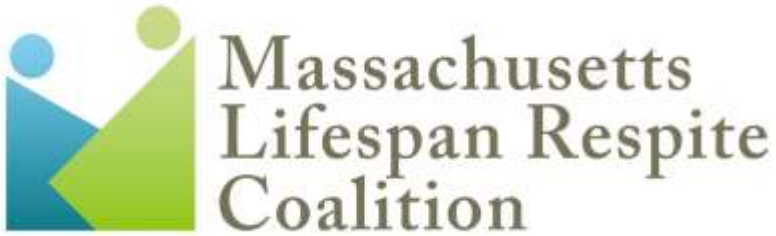
Evaluation's Role

- What is evaluation? Are we doing what we said we'd do?
- Why evaluation? Are we demonstrating value and impact?
- Telling our story to persuade others to join in our efforts.
- Demonstrating our value and impact means showcasing success, innovation, and lessons learned.



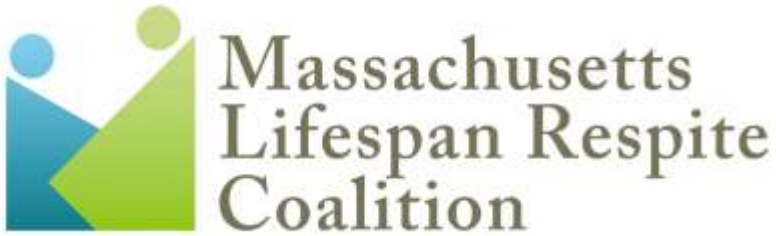
Evaluation Tools

- Demographic Information Form
- Client Level of Care Determination Chart
- Stress Survey (pre- and post-)
- Program Final Reports



Evaluation Data

- Participant demographics
- Care recipient level of care
- Stress level
- Total participants served
- Total respite hours provided
- Program description
- Success Stories and Challenges



Evaluation Opportunity: Discovery

Innovation: to discover new ways of meeting unmet respite needs

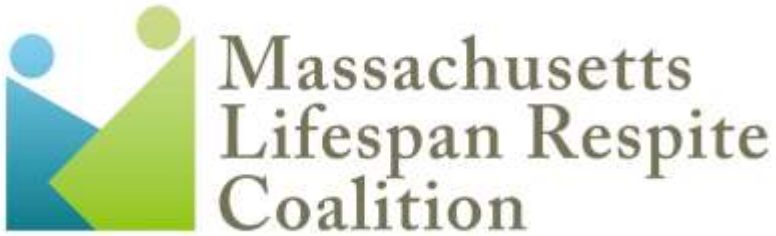
Innovation: 3 strategy areas

- Programming
- Outreach targeting underserved populations
- Leveraging resources by expanding collaborations

- ▶ Trying New Models and Documenting What Works!

Evaluation Challenges

- Data Collection
 - Implementing stress surveys
 - Additional missing data: demographics
- Comparisons of Services
 - Types of respite received: apples and oranges
- Cost Effectiveness Assessment
 - Total participant hours/other variables
e.g. staff hours



Examples of Successes: Innovative Programming

Innovative Programming: Respite Revolution developed by the Paul Center for Learning and Recreation

- Volunteer groups, caregiver forum, sensory garden and fire pit, family activities (family swim, etc.)
- 68 participants (31 caregivers/37 students)

Cultivated a range of sustainable community resources in responding to the specific needs of the local community.

Paid Home-Care Workers – Oak Square YMCA's Respite Membership Program

- Increased strength, sense of independence and self-esteem, improved healthy lifestyle
- Takeaway – innovative but not cost effective; going forward – target this population but work with HR

Cultural Minorities – Advocates and JFS Metrowest and JF&CS

- Close-knit cultural groups initially resistant to respite and distrustful of outsiders: Spanish-, Portuguese-, and Russian-speaking

Higher Income – Old Colony Elder Services

Growing Collaborations/Leveraging Community Resources/Existing Infrastructure – Berkshire ARC and Hockomock Area's YMCA's MS Wellness Programs

“This project challenged BCARC to reach out to other agencies that we normally don't work with on a daily basis... The result was outstanding with families being able to receive help and get the respite they needed. This also provided a wonderful opportunity and as a result project staff attends monthly networking meetings regarding caregiving and healthcare.”



Cost Effectiveness

- Measurement Challenges: total cost should include staff hours, equipment, etc. = all costs included in providing a service.
 - Issue: Uneven and limited data for more complex modeling
- One Measure: cost per participant respite hour
- Most effective were those using existing infrastructures – exs. aging and disabilities networks

Stress Reduction

- Strong qualitative anecdotes
- Only 75 post-stress surveys (126 pre-surveys)
- The three programs most successful in reducing stress were also top innovators: Berkshire Arc, Oak Square YMCA, and Old Colony.
- Caregivers of individuals requiring highest level of care experienced 2.5 times the stress reduction of those caring for someone with moderate needs and 4 times the stress reduction of those caring for someone with mild needs.

Voices of Success

My name is Shirley. I have been a caregiver for my daughter Alicia since 1999. She attends B.Fit!, a wellness program at The Boston Home. This service provides me with respite as well for 4 days a week....provid(ing) me with emotional and physical respite. I enjoyed them very much. My favorite session was the personal massages therapy and Zumba class...both a new relaxing and energizing experience.

The educational sessions were very resourceful...provid(ing) me with a better understanding of the disability rights and laws in Massachusetts from a lawyer, also knowledge of new support services in the community from an Options Counselor.

Thank you for caring for the caregivers!



Mr. L. is an 86 year old Holocaust survivor who lives with his wife, also a Holocaust survivor. Mrs. L. did not feel comfortable leaving her husband alone. She felt strongly that it was her job to be with him all the time. Their social worker from the Holocaust Program suggested the Respite Reassurance Program.

Having been already acquainted with two of our (Jewish Family & Children Services) workers...it was relatively easy for Mrs. L. to decide to take advantage of the respite time. She preferred one of the two workers to stay alone with Mr. L. and, understanding that trust is an important component of respite care, we were able to accommodate that. Now Mrs. L. is able to leave the house and babysit her grandchildren during the week.

Recommendations

- Use a family systems approach
- Focus innovation in three strategic areas: programming, targeting the underserved, and growing collaborations
- Fund technology such as Hoyer Lifts
- Segment our market and use targeted marketing
- Cultivate and train volunteer ambassadors
- Contain cost by leveraging and cross-training staff and volunteers



- Develop caregiver forums to tap caregivers' expertise
- Offer a wide array of respite options
- Grow cross-sector collaborations leveraging provider networks
- Use simple evaluation tools and protocols and provide training and ongoing technical support for data collection.
- Develop a model for measuring cost effectiveness that includes total cost of providing each type of service such as staff time (training, data collection), in-kind time and equipment.

Part II: Your Turn

- ▶ Complete Form Individually – to be collected

- ▶ Discuss group's experiences: refer to handout inventory
 - Evaluation Strategies
 - Evaluation Successes
 - Evaluation Challenges

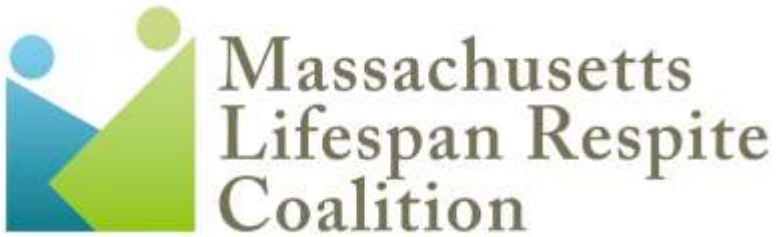


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See Handout: Inventory Worksheet

The screenshot shows a Microsoft Word document titled "Workshop Evaluation Inventory Worksheet". The ribbon is set to "Table Tools" with the "Table" tab selected. The document content includes a title "Evaluation Strategies for Respite Programs - National Inventory Sample" and a table with 7 columns and 6 rows. The table headers are: Program Name and Location, Types of Services Offered, Targeted Population, Desired Outcomes, Evaluation Tools, Evaluation Successes, and Evaluation Challenges. The table body contains five empty rows for data entry.

Program Name and Location	Types of Services Offered	Targeted Population	Desired Outcomes	Evaluation Tools	Evaluation Successes	Evaluation Challenges



Collective Lessons and Strategies

- ▶ Evaluation Strategies for Moving Forward
- ▶ Next Steps
- ▶ Anticipated Challenges
- ▶ Strategies for Navigating Obstacles



Massachusetts Lifespan Respite Coalition





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Questions?

Thank you!