Catherine Cutler Institute
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Office of Aging and Disability Services

Respite for ME Grants

Final Evaluation Report

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Table of Contents

Acknowledgements

The Maine Department of Health and Human Services issued a Request for Proposal (RFP #202109133) in September 2021 for an external evaluation of the Respite for ME Grants pilot program and awarded the contract to the Catherine Cutler Institute, Muskie School of Public Service, University of Southern Maine. This evaluation was funded under agreement #ADS-22-9006.

Executive Summary

Highlights

- Family caregivers often experience burdens and financial strain due to caregiving, and respite and other services can alleviate these impacts.
- The Respite for ME Grants pilot program aligned eligibility for respite services with the National Family Caregiver Support Program. It allowed caregivers to identify the services that best meet their support needs.
- Maine's Area Agencies on Aging (AAAs) began enrolling caregivers in the Respite for ME Grants pilot program on October 1, 2022. Caregivers were reimbursed up to $2,000 for approved services in Year 1 of the pilot and $5,171 in Year 2.
- The AAAs confirmed eligibility and enrollment into the program within two weeks of application.
- Most caregivers began receiving services within one month of enrollment.
- Caregivers who participated only in Year 2 of the pilot experienced significant improvement in most outcome measures. The proportion of caregivers with
  - High Stress scores decreased by 10%
  - High Depression scores decreased by 14%
  - Working caregivers saying caregiving had negative impacts on the ability to work decreased by 22%
- Although there were improvements, measures of caregiver burden and stress remained at medium or high levels throughout the pilot for most caregivers. This finding is not unique to the pilot and can be found in other studies on caregiver burden and stress over time.
- Caregivers said the services reimbursed by the program eased their financial worries and helped them be better caregivers for their loved ones.

Addressing Caregiving Burden in Maine

Family caregivers provide hours of unpaid, daily support to their loved ones, sometimes to the detriment of their well-being and financial stability. Maine's State-funded Respite Care Program (10-149 Ch. 5 State-funded Respite, Respite Care for People with Alzheimer's Disease or Related Disorders) relieves some of these burdens by providing respite services. Still, it has been available only to caregivers whose care recipient has a diagnosis of Alzheimer's disease or related dementia and limited liquid assets. The federally funded National Family Caregiver Support Program expands eligibility for respite by including caregivers of older adults, older adults caring for adult family members with disabilities, and grandparents who have assumed responsibility for minor grandchildren or other minor relatives. The older adult care recipient must need assistance in at least two Activities of Daily Living[*] (ADLs) or require substantial supervision due to cognitive impairment or mental health condition.

Respite for ME Grants Pilot

The 2021 Maine Jobs & Recovery Plan established the Respite for ME Grants pilot program to expand respite services to a broader group than existing respite programs through aligning caregiver eligibility definitions with the National Caregiver Program but not requiring certain diagnoses or minimum levels of ADL assistance for the care recipient. The Respite for ME Grants pilot also provided flexibility in the type of services available to reduce caregiver burden, intent to place their care recipient in a facility, and financial strain. The pilot operated for

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[*] Activities of Daily Living include bathing, dressing, using the bathroom, eating, getting out of bed, transferring, and locomotion.

two years, October 1, 2022 – September 30, 2024, and was administered by Maine's five Area Agencies on Aging.

After enrolling into the Respite for ME Grants program, caregivers were assessed on measures of burden, including stress and depression, how much caregiving presented a financial strain, and other measures. Area Agency on Aging staff assisted caregivers in identifying and obtaining services to meet their needs, such as respite, assistive technology, home modification and repair, chores, self-care, and others. Pilot funds reimbursed the caregivers up to $2,000 for approved services in Year 1 and up to $5,171 in Year 2. A follow-up assessment of caregiver burden was conducted 90 days after the caregiver started receiving services in each year of participation

Evaluating the Pilot

The Maine Department of Health and Human Services contracted with the University of Southern Maine to evaluate the Respite for ME Grants pilot. Evaluation elements required by the Legislature included program efficiency measures, a comparison of the service cost and use in Respite for ME Grants and State-Funded Respite, demographics of pilot participants, and demographics of caregivers on any waitlists for the pilot program. The evaluation team analyzed administrative, demographic, and pre-post assessment data to determine the impact of the pilot program on caregiver burden, intent to place, financial strain, and other outcome measures. To account for the impact of the different grant amounts in Year 1 and Year 2, the evaluation team assigned caregivers to different cohorts based on when they participated in the program (Figure 1).

Figure 1 Cohort assignments for evaluation

Cohort 1: Enrolled in Year 1 only.

Cohort 2: Enrolled Year 2 only.

Cohort 3: Enrolled in Year 1 and started receiving services between 7/1/2023 and 9/30/2023 and re-enrolled in Year 2 between 10/1/23 and 12/31/23.

Cohort 4: Enrolled in Year 1 and had a follow-up before 7/1/23 and renrolled in Year 2 on or after 10/1/23

The largest group of participants, Cohort 2, participated only in Year 2 and received up to $5,171 in reimbursed services.

Table 1 Caregivers who enrolled, used services, and had follow-up assessments for the evaluation

Cohort	Enrolled	Used Services	Had a Follow-Up Assessment
Cohort 1	159	102	65
Cohort 2	442	358	222
Cohort 3	121	121	101
Cohort 4	119	118	99
Total	**841**	**699**	**487**

Note: Follow-up groups include anyone from year one and/or year two who received at least one Follow Up Score.

The evaluation team also conducted a survey and key informant interviews to gather more nuanced, qualitative data about the impact of the grants on participants. The first-year evaluation report can be found on the OADS website. This final evaluation report covers the first 22 months of participant experience, service use, and spending.

Summary of Findings

Program Efficiency Measures

Enrollment Process Timeframes

Most caregivers accessed Respite for ME services within one month of enrollment.

Table 2 Program efficiency measures in Year 1 and Year 2

Program Efficiency Measures Year 1	
Average days between application and eligibility confirmation	12
Average days between eligibility confirmation and receipt of services	32
Program Efficiency Measures Year 2	
Average days between application and eligibility confirmation	11
Average days between eligibility confirmation and receipt of services	21

Note: This table includes only the 339 Year 1 caregivers who used services in the first year of implementation and only the 580 Year 2 caregivers who used services in the first ten months of year two of implementation, not all who enrolled.

Service Use and Demographics of Participants

Respite for ME Grants Compared to State-funded Respite

Over the two years of implementation, 841 caregivers enrolled in the Respite for ME Grants pilot, though not all who enrolled used services reimbursed by the program. Table 3 shows the number of people who used services through Respite for ME Grants or the State-funded Respite programs, October 1, 2022, through July 31, 2024.

Table 3 Respite for ME Grants compared to State-funded Respite

	Respite for ME Grants Y1	State-funded Respite Y1	Respite for ME Grants Y2*	State-funded Respite Y2*
Total participants who used services (unduplicated)	353	211	580	127
Respite				
In-Home	165	177	281	113
Out-of-Home Day or Night	10	4	10	1
Adult Day Services	14	43	66	16
Respite Other	--	8	3	--
Assistive Technology/Devices	145	10	289	7
Home Modifications/Repairs	62	11	106	4
Other Respite for ME Services	230	-	403	-
Cost	$343,912	$666,310	$1,380,566	$428,896

	Respite for ME Grants Y1	State-funded Respite Y1	Respite for ME Grants Y2*	State-funded Respite Y2*
Cost of other services	$197,488	--	$590,742	--
Total Cost	**$541,399**	**$666,310**	**$1,971,308**	**$428,896**

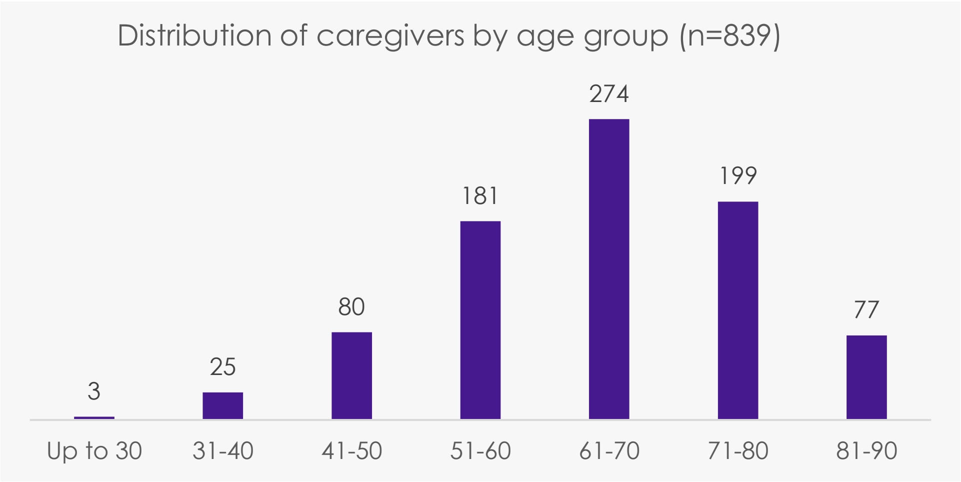
*Preliminary data pending final reconciliation. Y2 shows 10 months of data from 10/1/2023 - 7/31/2024.

Demographics of Respite for ME Grants Participants

Age

The average age of caregivers was 65 years old

Figure 2 Over 65% of caregivers were over 60 years old.



Race/Ethnicity

Like statewide statistics, most enrolled caregivers identified as non-Hispanic and White (98%).

Table 4 Race and ethnicity demographics of Respite for ME Grants caregivers

Race	Number	Percentage
White	825	98%
Black or African American	7	1%
Asian or Asian American	4	0.5%
Native American	4	0.5%
Other/Unknown	1	0.6%
Ethnicity		
Non-Hispanic or Latino	826	98%
Hispanic or Latino	8	1%
Unknown	7	0.8%

Gender Identity

Over three-quarters of Respite for ME Grants caregivers identified as women.

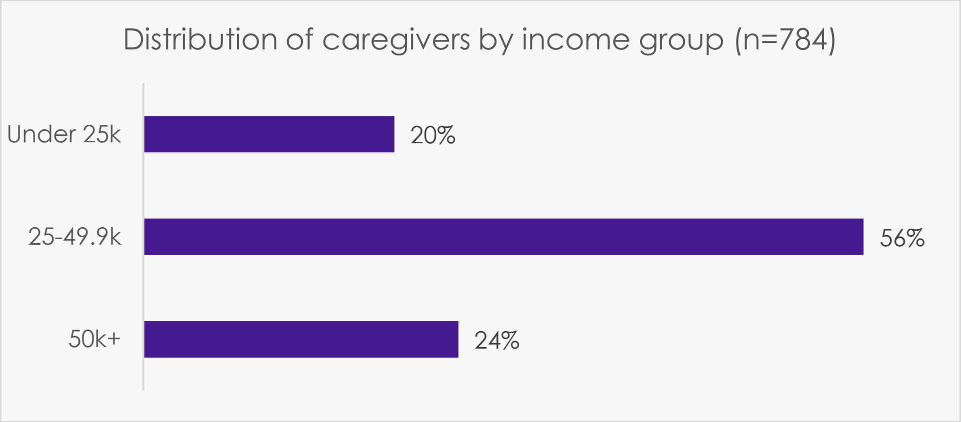
Table 5 Gender identity of Respite for ME Grants caregivers

Gender Identity	Number	Percentage
Women	638	76%
Men	201	24%

Income

Overall, 76% of caregivers had annual incomes under $50,000. Twenty percent had annual incomes under $25,000.

Figure 3 Income levels of Respite for ME Grants caregivers

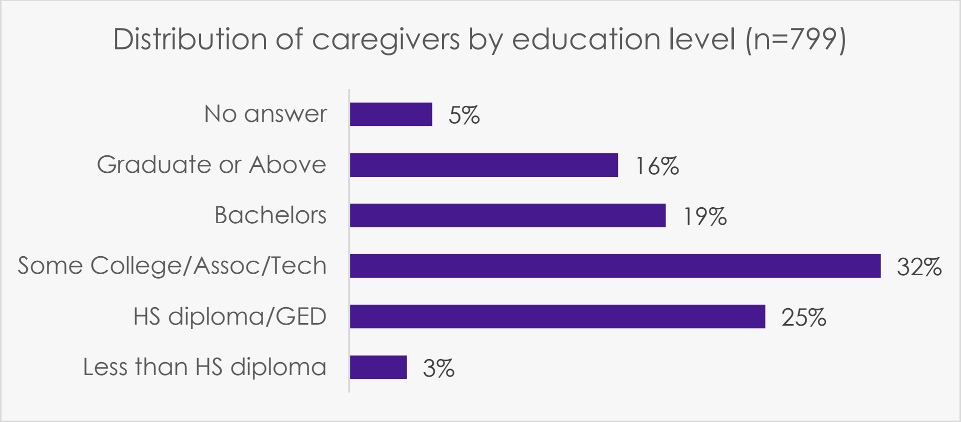


Note: Income data was missing from 57 caregivers.

Education level

Over half of the caregivers had a high school level or some college education.

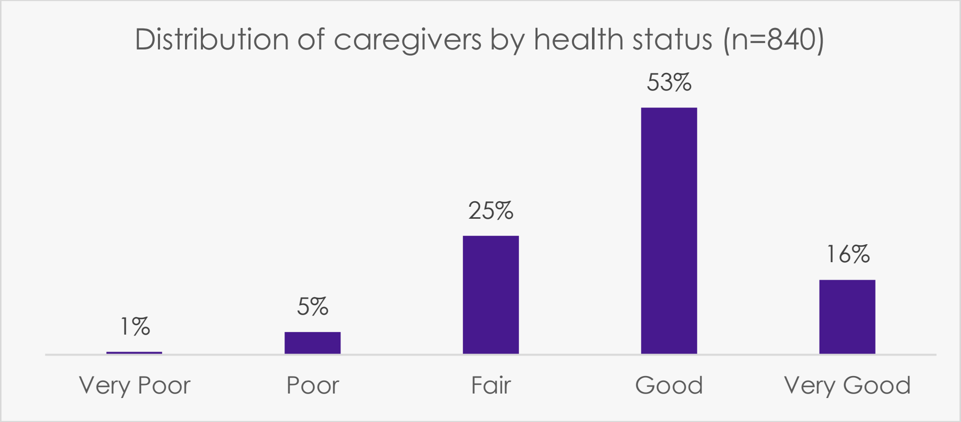
Figure 4 Education level of Respite for ME Grants caregivers



Initial Health Status

Over half of caregivers said their health status at enrollment was good, but 30% said it was either poor or fair.

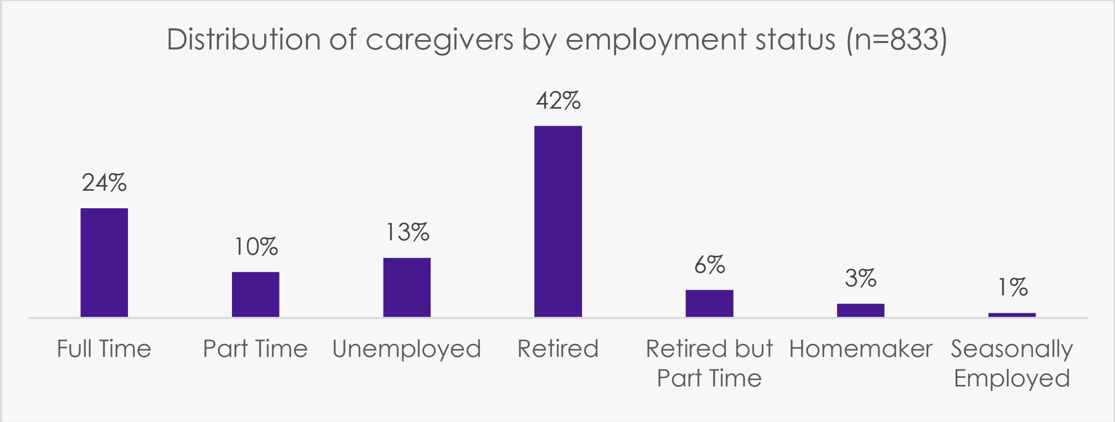
Figure 5 Health status of Respite for ME Grants caregivers



Initial Employment Status

Forty-two percent of caregivers were retired, and 41% were working at some level.

Figure 6 Employment status of Respite for ME Grants caregivers



County of residence

Cumberland County had the most caregivers enrolled, followed by Kennebec County, York County, and Aroostook County.

Table 6 Respite for ME Grants caregivers by county

County	Number enrolled	Percent
Androscoggin	33	4%
Aroostook	104	12%
Cumberland	144	17%
Franklin	14	2%
Hancock	30	4%
Kennebec	136	16%
Knox	26	3%
Lincoln	29	3%
Oxford	20	2%
Penobscot	82	10%
Piscataquis	2	0%
Sagadahoc	12	1%
Somerset	35	4%
Waldo	29	3%
Washington	9	1%
York	136	16%

Outcomes and Caregiver Experience

There were a few significant findings in all the cohorts, but Cohort 2 improved on the most outcome measures. Feedback from caregivers across the pilot showed they valued the financial assistance provided by the grants, and that it helped them attend to their own needs.

After receiving Respite for ME Grants services for 90 days, the proportion of caregivers participating only in Year 2 with…

- High Relationship burden declined by 7%
- High Stress burden declined by 10%
- High Objective burden declined by 5%
- High Depression declined by 14%
- Low financial strain increased by 6%
- Negative impacts on the ability to work declined by 22%
- Negative impacts on job performance declined by 9%

Respite for ME Grants Program caregivers said the grants…

- Helped alleviate financial stress and worry
- Improved their ability to work by helping them purchase respite services
- Allowed them to attend to their own mental and physical health needs
- Enabled them to better care for their loved ones

Introduction & Purpose

Governor Mills' 2021 Maine Jobs & Recovery Plan, approved by the Legislature, invested nearly $1 billion in federal American Rescue Plan Act funds to improve the lives of Maine people and families, help businesses, create good-paying jobs, and build an economy poised for future prosperity. The Maine Jobs and Recovery Plan legislation (P.L. 2021, Ch. 483, Part CC) directed the Department of Health and Human Services (the Department) to establish the Family Caregiver Grant (hereafter Respite for ME Grants) pilot program to increase the number of families served under existing respite programming, alleviate costs associated with providing in-home care of an adult, provide a family caregiver grant to increase economic security for family caregivers, and examine the needs and preferences of the families using respite and other pilot program services.

The Department issued a Request for Proposal (RFP #202109133) in September 2021 for an external evaluation of the Respite for ME Grants pilot program. After reviewing three proposals, the Department awarded the contract (#ADS-22-9006) to the Catherine Cutler Institute, Muskie School of Public Service, University of Southern Maine (USM).

The key objectives of this evaluation are to assess program efficiency, compare the service use and cost in Respite for ME Grants and State-funded Respite, provide demographic information about participants, and determine the pilot's impact on caregiver burden and stress measures, intent to place their care recipient in a facility, financial strain of caregiving, and ability to work.

This final evaluation report includes data from the twenty-two months of implementation, October 1, 2022, through July 31, 2024, to describe the total number of people who received respite services, assistive technology, and home modifications and the dollars spent on these services under Respite for ME Grants compared to existing respite programming use and expenditures over the same period, measures of program efficiency, caregiver characteristics, and program impact on caregiver stress and burden.

This study received a determination from the USM Office of Research Integrity and Outreach on August 31, 2022, that the activities carried out under the evaluation of the Respite for ME Grants program did not fall under the definition of research as described in 45 CFR Sect. 46.102(1), and did not require further review or determination by the USM Institutional Review Board (Protocol HRPP #083022-90).

Caregiving and Respite in Maine

Highlights

- Family caregivers provide hours of unpaid care, sometimes to the detriment of their own well-being.
- Respite services can alleviate caregiver burden, but in Maine, these services had not been available to many caregivers.
- The Respite for ME Grants program aligned eligibility for respite services with the National Family Caregiver Support Program and allowed caregivers to identify the services that best met their support needs.
- Concurrently with the Respite for ME Grants program, Maine also implemented the Tailored Caregiver Assessment and Referral™ protocol to identify caregiver needs and develop care plans to meet them.

Informal caregivers, typically family members, are the backbone of Maine's system of long-term services and supports. Each year, they provide millions of hours of unpaid care to their loved ones who need assistance due to age, chronic illness, or disability.[1] With the shortages in direct care workers and the expense of formal services, family caregivers play a central role in assisting their loved ones with activities such as bathing, dressing, eating, grocery shopping, housekeeping, and paying bills. This assistance enables people to remain safely at home in the communities of their choice. It may delay nursing home placement.[2, 3, 4] Some older adults also play an important role as caregivers for their grandchildren or other minor relatives in the absence of a parent.

Caregiving can have adverse impacts on the physical and mental health of caregivers, resulting in increased anxiety and depression as well as decreased preventive health activities.[5, 6, 7] In addition, family caregivers may need to reduce working hours or leave the workforce entirely, causing financial strain. Job performance can suffer when workers go in late, leave early, or take time off due to caregiving responsibilities.[1] A 2023 survey of Maine caregivers[8] found that 65% went in late, left early, or took time off during the day to provide care, 17% went from working full-time to part-time or cut back on hours, and 16% left a job due to caregiving. Forty percent of caregivers reported that caregiving was somewhat or very much a financial strain.

Supporting caregivers by assessing their burden and referring them to available community resources has been shown to improve their burden and depressive symptoms.[9] Respite services allowing caregivers to take a break from caregiving responsibilities result in decreased burden, improved emotional well-being, and the ability to attend to personal tasks.[10,11]

Respite Options in Maine

Maine's Area Agencies on Aging (AAAs) administer two respite care programs, the State-funded Respite Care for People with Alzheimer's or Related Disorders (10-149 Ch. 5 State-funded Respite) and the federally funded National Family Caregiver Support Program (FCSP) (Title III-E of the Older Americans Act).

Eligibility for the State-funded Respite program focuses on the care recipient. It is limited to adults of any age with a physician's clinical assessment of Alzheimer's disease or related disorder (ADRD) who meet asset limits. Services include in-home respite care, Adult Day services, out-of-home respite in a residential or nursing facility, as well as home modifications[†] and assistive technology and devices.

[†] There is a $2,000 lifetime limit for home modifications.

The FCSP has broader eligibility criteria and includes:

- Adult family members or other informal caregivers ages 18 or older providing care to individuals ages 60 years or older.
- Adult family members or other informal caregivers ages 18 or older providing care to individuals of any age with ADRD.
- Relatives ages 55 or older, not including parents, providing care to children under 18.
- Relatives ages 55 or older, including parents, providing care to adults ages 18 to 59 with disabilities.

Services available under the FCSP include providing information about available services, assistance accessing services, caregiver counseling and support, respite, and limited supplemental services. Respite and supplemental services are available for all older relative caregivers, but only to caregivers of older adults or those with ADRD, whose care recipient needs assistance with at least two Activities of Daily Living (ADLs) or has a cognitive or other mental impairment requiring substantial supervision. Most FCSP funding goes toward providing information, assistance accessing services, outreach, and support groups. Home modifications under the FCSP have a $5,000 lifetime limit, and supplemental services can be no more than 20% of the FCSP budget.

Respite for ME Grants Pilot

Through aligning eligibility with the FCSP and eliminating the care recipient ADL or cognitive impairment requirements, the Respite for ME Grants pilot intended to enable more caregivers to receive respite and other services they identified to best meet their needs. The Respite for ME Grants pilot offered the same services as the State-funded Respite and FCSP as well as expanded service options. It focused on the caregiver, allowing them to identify additional services that could reduce their burden. Caregivers were reimbursed for approved self-care services like gym memberships and fitness classes, summer camp registration fees for grandchildren under their care, house cleaning, and yard maintenance. Additionally, there was no lifetime dollar limit on home modifications.

In the first year of the pilot, Respite for ME Grants offered a wider range of reimbursable services than the State-funded Respite program but with a lower annual benefit limit of $2,000 (Table 7). For the second implementation year, the annual benefit amount for Respite for ME rose to $5,171 on October 1, 2023, the same level as the State-funded Respite program, creating better parity between the two programs. However, the State-funded Respite program benefit amount rose to $5,303 on January 1, 2024.

Table 7 Comparison of Respite for ME Grants and State-funded Respite services

Services and Subtypes Allowed	Respite for ME	State-funded Respite
Assisted transportation	X	
Assistive devices	X	X
Assistive technology Durable Medical Equipment General Technology Personal Response System	X	X
Caregiver individual counseling	X	
Caregiver training	X	
Chore Housework Yardwork	X	
Consumable supplies Incontinence	X	

Services and Subtypes Allowed	Respite for ME	State-funded Respite
Home modifications/repairs Accessibility Health and Safety	X	X*
Homemaker	X	
Legal/financial consultation	X	
Respite Adult Day In-Home Out-of-Home Day Out-of-Home Overnight	X^	X
Self-care Fitness Class Fitness Equipment Health and Wellness	X	
Transportation	X	
Annual dollar limit	$2,000, Year 1 $5,171, Year 2	$ 4,778 to $5,303+

* Lifetime cap of $2,000 for home modifications/repairs.

^ Respite for ME Grants allowed reimbursement for additional respite activities such as summer camp fees for dependent grandchildren.

+The State-funded Respite program benefit amount was $4,778 on 10/1/2022. It increased to $5,171 on 1/1/2023 and $5,303 on 1/1/2024.

Pilot Planning and Implementation

Planning Process

Beginning in October 2021 and continuing through early summer 2022, OADS engaged a Stakeholder Group to develop the implementation structure of the pilot program, including eligibility requirements, outreach strategies, program evaluation and outcomes of interest, and sustainability and payment methods. The Stakeholder Group (Table 8) was made up of Executive Directors of Maine's five AAAs (Figure 7) as well as leaders of aging services and advocacy organizations and members of the caregiving community.

Table 8 Respite for ME Grants Pilot Stakeholder Group

Stakeholder Group	Affiliation
State Agency	Office of Aging and Disability Services Consultant
Area Agencies on Aging	Aroostook Agency on Aging Eastern Area Agency on Aging SeniorsPlus Southern Maine Agency on Aging Spectrum Generations
Advocacy Groups	AARP Alzheimer's Association Equality Maine Maine Center for Economic Policy Maine Council on Aging Maine People's Alliance NAMI

Stakeholder Group	Affiliation
Service Providers/Associations	Home Care and Hospice Alliance Legal Services for Maine Elders Long-Term Care Ombudsman Program MaineHealth VA Togus
Maine Tribes	Mi'kmaq Nation Pleasant Point Passamaquoddy Penobscot Indian Nation
State Legislature	Representative Kristen Cloutier
Care Partner	Ron Phillips
Evaluator	University of Southern Maine

Figure 7 Maine's five Area Agencies on Aging and counties served.

Aroostook Area Agency on Aging	• Aroostook
Eastern Area Agency on Aging	• Hancock, Penobscot, Piscatiquis, Washington
SeniorsPlus	• Androscoggin, Franklin, Oxford
Southern Maine Area Agency	• Cumberland (not Brunswick or Harpswell), York
Spectrum Generations	• Cumberland, (Brunswick and Harpswell only), Kennebec, Knox, Lincoln, Sagadahoc, Somerset, Waldo

Subcommittees were assigned different policy areas to investigate and recommend to the Stakeholder Group for final decision-making. Out of this planning effort, OADS developed a Process and Documentation guide for the AAAs that outlined the steps they and caregivers must take to be enrolled in the program, including timeframes for the AAAs to complete enrollment activities (see Appendix A).

Financial Hardship

To comply with the federal funding requirements of the Maine Jobs and Recovery Plan, caregivers must have experienced economic hardship due to COVID-19 and submit a "hardship attestation" form to the AAA to be eligible for the program. Hardship included job loss, reduced household income, significant costs of healthcare, childcare, or dependent care, or other financial hardship.

Caregiver Assessments

In addition to the Respite for ME Grants pilot program, the Department implemented a new assessment and care planning system, the Tailored Caregiver Assessment and Referral™ protocol, TCARE®, to help identify the level of need for services among caregivers and develop a person-centered care plan that meets their needs. TCARE® is an evidence-based caregiver assessment platform that quantifies caregiver burden and stress levels and identifies services and resources available in the caregiver's community that could help them. Before the launch of the pilot, AAA staff were trained in conducting TCARE® assessments and entering the data into the TCARE® platform. All caregivers in the Respite for ME Grants pilot program had a TCARE® assessment and care planning process.

TCARE® measures several aspects of burden, depression, and intent to institutionalize their care recipient (Table 9).

Table 9 TCARE® Measure Definitions.

TCARE® Measure	Definition
Identity discrepancy	The affective psychological state that occurs when there is a disparity between the care activities in which a caregiver is engaging and those activities that would be consistent with his or her identity standard
Stress burden	A generalized form of negative affect that results from caregiving.
Relationship burden	Demands for care and attention over and above the level that the caregiver perceives is warranted by the care recipient's condition.
Objective burden	A negative psychological state that results from the perception that caregiving activities and responsibilities are infringing on other aspects of the caregiver's life, including time and energy to address other family obligations, leisure activities, and personal needs
Depression	Measured using a four point, 10-item short version of the Center for Epidemiological Studies-Depression (CES-D) scale capturing four underlying dimensions of depressive symptoms including dysphoria, somatic complaints, positive affect, and interpersonal distress
Intention to place	The caregiver's plan to place the care recipient in an alternate care setting and abdicate the role of primary caregiver.

Prior to the implementation of the Respite for ME Grants pilot, new data fields specific to the pilot were added to the OADS/AAA administrative platform, WellSky Aging and Disability case management software (WellSky). These fields included dates of application to the program and when the caregiver was determined to be eligible, the date of the first service paid for under the program, and assessment questions about the financial strain of caregiving, the impact of caregiving on the caregiver's ability to work, and job performance factors such as arriving late and leaving early. The Respite for ME Grants evaluation used data collected through both TCARE® and WellSky assessments.

Implementation

Governor Mills announced the program's start on September 28, 2022, and OADS and the AAAs launched their marketing activities. ETHOS Marketing developed statewide multiplatform ads, and marketing materials with the tagline, "Your Care Matters Most of All," were distributed to the AAAs to assist in outreach. Google, Facebook, and Instagram ads targeted rural caregivers and "sandwich" caregivers—women between 40 and 64 years old. AAAs began receiving inquiries and applications on October 1, 2022. In the first few months of implementation, local and national news outlets, including Forbes and Barron's, produced articles about the program.

OADS met with the AAAs on a bi-weekly basis throughout the start-up period, October 2022-April 2023, and then monthly beginning in May 2023, to discuss policies and procedures, enrollment or assessment issues, and updates from the AAAs on how caregivers were receiving the program. After March 2024, OADS and the AAAs decided to address pilot administrative issues at the bi-monthly FCSP meetings instead of having a stand-alone Respite for ME Grants program meeting.

To assist the AAAs in the enrollment process, OADS created the application form, economic hardship attestation form, eligibility, and ineligibility determination letters, and FAQs about the program to be shared with potential enrollees and community partners.

Enrollment and Assessment Process

Once caregivers were confirmed eligible to participate and the AAA had received all supporting enrollment documentation, including the financial hardship attestation form, the AAA sent a confirmation letter to the caregiver, activated their enrollment in the program, and began scheduling the assessment and care planning process.

In the first two months of the implementation, AAAs noted the online TCARE® assessment platform was slow with long lag times, adding administrative time to the AAAs to complete care plans within the platform. Additionally, the TCARE® Resource Directory designed to assist AAAs in identifying services available to meet caregivers' needs was outdated and, in some cases, irrelevant. The AAAs also said the TCARE® assessment could be lengthy and burdensome for caregivers whose caregiving activities often constrained their time. They noted that the onboarding process could take several hours of staff time per enrollee. By January 2023, the TCARE® platform issues were improving, and newly hired Family Caregiver Specialists at some AAAs alleviated administrative burdens.

At the start of the pilot, AAAs were required to have completed the TCARE® assessment and care plan within 30 days of receiving an application. However, delays in caregiver submissions of the hardship attestation form impacted the date of enrollment and scheduling of the TCARE® assessment. In response, OADS changed the time requirement for the completed TCARE® assessment and care plan to 60 days. This allowed the AAAs and caregivers more time to collect all the necessary documentation to complete the enrollment, TCARE® assessment, and care planning.

Reassessment

Respite for ME Grants participants were expected to complete a follow-up assessment 90 days after they started receiving services under the program. The data from the initial and follow-up assessments formed the basis of the analysis of the evaluation outcome measures. After the first several months of implementation, AAAs noted that some caregivers refused to go through the follow-up assessment after being reimbursed for services. AAA staff made notes within the WellSky platform when this occurred, and OADS drafted a Caregiver Participation Letter reiterating the expectation that caregivers complete the 90-day reassessment. Over the two-year pilot, approximately 30% of caregivers did not complete a follow-up assessment.

Limited Enrollment in Year 1

It was anticipated that the Respite for ME Grants pilot program would attract many caregivers who had not had access to reimbursement for respite services before and that the AAAs might need to develop a waitlist for participants. However, during the first three months of implementation, there were only 123 caregivers enrolled. One hundred twenty-six caregivers enrolled in the second quarter of implementation, 79 enrolled in the third quarter, and 77 enrolled in the fourth quarter ending on September 30, 2023, for total enrollment in the first year of 405. Enrollment levels never necessitated a waitlist throughout the first year of implementation.

Changes in Year 2

As the pilot program entered its fourth quarter in July 2023, OADS, the AAAs, and USM discussed the possibility of Year 1 caregivers either starting to receive services in July or later or enrolling and receiving services in the final quarter, and reapplying for Year 2 in October. These scenarios could result in caregivers having initial or follow-up assessments in Year 1 very close to new initial assessments early in year 2. Out of these discussions, OADS developed a guidance document for the AAAs to minimize the burden on AAAs and caregivers while preserving the integrity of the evaluation by continuing to collect baseline enrollment and follow-up assessment data. For example, caregivers who had Year 1 follow-up assessments in August and who reapplied in October could have their follow-up assessment count as an initial assessment for Year 2. Instructions for the assessment/reassessment procedure for participants who enrolled between July 2023 to December 2023 were given to AAAs during this transition from Year 1 to Year 2. This timeframe within the pilot program was referred to as "Shoulder Season" and is further explained in the Evaluation section and Appendix A.

Year 2 Implementation Experience

The second year of the Respite for ME Grants pilot program began on October 1, 2023. The AAAs were allowed to rollover unspent Year 1 Respite for ME Grants funding in the second year. With the increase in the Respite for ME Grants pilot grant amount in Year 2 from $2,000 to $5,171, the AAAs noted increased enrollment compared to the first year. In addition, many Year 2 enrollees were repeat participants. The enrollment continued to increase, and by early February, reimbursements to caregivers had already surpassed total spending for Year 1. Some AAAs had to implement waitlists for the program. Only seven caregivers were on a waitlist at any point in Year 2. AAAs with waitlists were allowed to subcontract with other AAAs that had available Respite for ME Grants funds to enable the caregivers to come off the waitlist.

The evaluation's need for pre-post assessment data for people who enrolled or re-enrolled during the Shoulder Season became an administrative burden on some AAAs. Tracking which Year 1 initial or follow-up assessment could be used as an initial assessment in Year 2 for caregivers who either enrolled late or spent funds late in Year 1 was sometimes confusing for staff. After December 31, 2023, assessments for all re-enrolling caregivers followed the original process with an initial assessment and 90-day follow-up after the first date services were received for the rest of the pilot period.

Some caregivers across both years did not spend their grant funds right away as expected. In Year 2, with the increased enrollment, OADS and the AAAs discussed how this impacted the need for a waitlist. The AAAs wondered if they could discharge participants from the program if they had not spent their funds. However, this was not allowed as the eligibility confirmation letter specified that the caregiver would be eligible through September 30, 2024. OADS encouraged the AAAs to follow up with the caregivers to discuss their plans for spending the funds and to let them know they were available on a first-come, first-served basis.

The AAAs had fewer issues with the TCARE® platform in Year 2. OADS shared Year 2 program guidance documents with the AAAs clarifying assessment timing and what could be reimbursed under the program.

The pilot ended on September 30, 2024.

Evaluation

Highlights

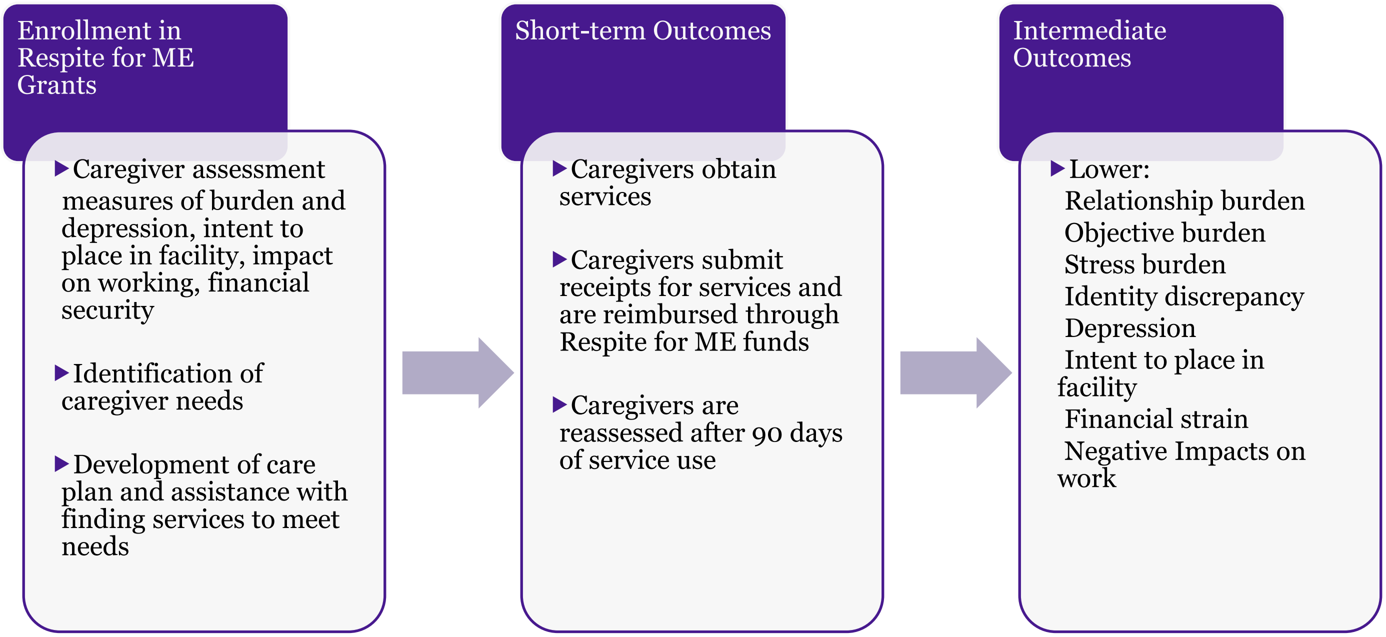
- Caregivers were assessed at enrollment and 90 days after first receiving services.
- The evaluation analyzed pre-post assessments of caregiver burden, intent to place, financial hardship, and other outcome measures.
- Program efficiency was measured by analyzing the time it took to determine eligibility for the program and how long it took caregivers to receive services after enrollment.

Evaluation Goals

The goals of this evaluation were to (1) describe program efficiency measures as required by the legislation authorizing Respite for ME Grants, and (2) evaluate the impact of Respite for ME Grants on caregiver burden, intent to place their care recipient in a facility, and financial strain of caregiving.

Figure 8 shows the guiding model of the evaluation and identifies the hypotheses tested: Enrollment in the Respite for ME Grants program would result in the caregivers receiving needed services that would lower their burdens as caregivers, reduce their intent to place their care recipient in a facility, and reduce the adverse impacts of caregiving on work, job performance, and financial strain.

Figure 8 Guiding Model for Respite for ME Grants Pilot Evaluation



Enrollment in Respite for ME Grants

- Caregiver assessment measures of burden and depression, intent to place in facility, impact on working, financial security
- Identification of caregiver needs
- Development of care plan and assistance with finding services to meet needs

Short-term Outcomes

- Caregivers obtain services
- Caregivers submit receipts for services and are reimbursed through Respite for ME funds
- Caregivers are reassessed after 90 days of service use

Intermediate Outcomes

- Lower:
  Relationship burden
  Objective burden
  Stress burden
  Identity discrepancy
  Depression
  Intent to place in facility
  Financial strain
  Negative Impacts on work

Evaluation questions

Answers to the following questions are intended to inform OADS, AAAs, the Stakeholder Group, and the Legislature about the implementation experience of the Respite for ME Grants program and whether it met the desired goals.

Program Efficiency Questions ((*) indicates element required by Legislature):

- How long did it take to determine eligibility for Respite for ME Grants?*
- How long did it take to receive services provided under Respite for ME Grants after application completion?*
- How many individuals received respite care, assistive technology, home modification under State-funded Respite and Respite for ME Grants?*
- What amount was expended for respite care, assistive technology, and home modification under State-funded Respite and Respite for ME Grants?*

- What are the demographic characteristics of caregivers receiving Respite for ME Grants funds?*
- What are the demographic characteristics of caregivers on the Respite for ME Grants waiting list?*

Program Impact Questions[‡]

- Do Respite for ME Grants services impact caregiver burden, stress, and well-being?
- Do Respite for ME Grants services impact caregiver intent to place their family member in a facility?[§]
- Do Respite for ME Grants services impact caregivers' ability to work or job performance?

Evaluation Methods

This evaluation used a mixed methods design utilizing quantitative and qualitative data. Participant data were entered into the WellSky and TCARE® platforms by Family Caregiver Specialists at each AAA. Program staff at OADS compiled the data and provided USM with deidentified Microsoft Excel files of administrative and assessment data. USM cleaned the data and built analytic files in Microsoft Excel and IBM® SPSS®29. In addition, USM regularly met virtually with the OADS and the AAAs throughout implementation to gather information on implementation issues and AAA and caregiver reactions to and experience

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[‡] The first evaluation report included an analysis of caregiver characteristics related to different services used. However, the level of detailed information required for the analysis was not available in Year 2 of the pilot, and so it is not included in this report.

[§] The legislation establishing the pilot required the evaluation to determine if the pilot delayed nursing facility placement. This type of analysis requires a longer analysis period and is not within the scope of this evaluation. Alternatively, we looked at changes in caregiver intention to place their care receiver in a facility.

with the program. Qualitative data was gathered from caregivers through an online survey in the spring of 2024 and key informant interviews in the summer of 2024.

Key Outcome Variables

The evaluation analyzed outcome variables to determine the impact of the program on caregivers (Table 10). A full list of variables can be found in Appendix B.

Table 10 Respite for ME Grants Evaluation Outcome Variables

Outcome Variable	Score Ranges (higher scores = higher burden) and Categories
Relationship burden	up to 40
Objective burden	up to 30
Stress burden	up to 25
Identity discrepancy	up to 40
Depression	up to 40
Intent to place	Yes/No
Impact of caregiving on work	Yes/No
Impact of caregiving on job performance	Yes/No
Financial strain of caregiving	Prefer not to answer Not Much at All Somewhat Very Much

Analysis Approach

Quantitative analysis

The evaluation used program administrative data to measure how quickly caregivers could be determined eligible for grant funds and receive services funded by the program, how many people used different services, and how much was spent on grant-funded services.

TCARE® and WellSky assessment data were analyzed using descriptive statistics, chi-square tests, independent samples t-tests, and one-way ANOVA with Tukey post hoc tests or Kruskal-Wallis tests to describe demographic characteristics of grant recipients and TCARE® scores Kolmogorov-Smirnov and Shapiro-Wilk tests of normality of dependent variables were conducted before all analyses of total TCARE® score (sum of Relationship, Stress, Objective, Depression, and Identity Discrepancy scores) and subscale scores. Initial TCARE® scores were normally distributed for Year 1 but nonparametric for Year 2. The subscales of burden scores were nonparametric. Wilcoxon matched-pair sign ranks tests and McNemar and McNemar-Bowker chi-square tests were used for analyzing changes in TCARE® measures of burden, intent to place in a facility, health status, and caregiving impact on caregiver work, job performance, and financial strain.

Cohort Analysis

To minimize the burden on AAAs and caregivers in the Respite for ME Grants pilot program, USM and OADS developed the “Shoulder Season” approach for assessing caregivers. This gave AAAs and caregivers the option to limit the number of assessments needed from July 1, 2023, of Year 1 to December 31, 2023, of Year 2, for caregivers who participated in both years during this timeframe.

To account for variation in funds available to caregivers in Year 1 to Year 2, caregivers were assigned to "cohorts" based on when they participated in the program. Individuals who participated only in Year 1 and received up to $2,000 were assigned to Cohort 1. Individuals who participated only in Year 2 and received up to $5,171 were assigned to Cohort 2. Those who participated in both years during shoulder season (July 2023 to December 2023) could have received $7,171 ($2,000 in Year 1 and $5,171 in Year 2) within the 6-month time and were assigned to Cohort 3. Those who participated in both years outside of shoulder season could have received up to $7,171 over a longer time and were assigned to Cohort 4. Cohort 3 and Cohort 4 represent individuals who participated in the Respite for ME Grants program for two years. However, they were evaluated separately to account for the impact of receiving the funds all at once or in a longer timeframe. Caregivers in each cohort were evaluated separately, with each participant represented once, even if they participated in both years. More information on the shoulder season process and cohort demographics can be found in Appendix A.

Figure 9 Cohort assignments

Cohort 1: Enrolled in Year 1 only.

Cohort 2: Enrolled Year 2 only.

Cohort 3: Enrolled in Year 1 and started receiving services between 7/1/2023 and 9/30/2023 and re-enrolled in Year 2 between 10/1/23 and 12/31/23.

Cohort 4: Enrolled in Year 1 and had a follow-up before 7/1/23 and renrolled in Year 2 on or after 10/1/23

Qualitative analysis

The evaluation team developed a two-pronged approach to gather qualitative data about caregiver experiences with the Respite for ME Grants pilot program. First, the team developed an online survey, administered in June 2024, to caregivers who had enrolled by April 2024 and shared a valid email address when enrolling in the program (n=458). A total of 192 complete survey responses were received. Second, the team followed up with survey respondents willing to be contacted to discuss their experiences in an interview (n=98). The team selected a random sample of 30 caregivers to interview via Zoom or telephone. The evaluation team developed a seven-question interview protocol based on the online participant survey, particularly probing for discussion regarding how the financial support and flexibility of the Respite for ME Grants program impacted their daily life, reduced their burden, and alleviated the financial strain of caregiving. All interviews included informed consent language and were recorded and transcribed. The responses were thematically analyzed using Microsoft Excel.

Findings

Highlights

- Respite for ME Grants caregivers used more Assistive Technology/Devices and Home Modifications compared to those using State-funded Respite.
- Most Respite for ME Grants caregivers were women with high levels of burden.
- After participating in Respite for ME Grants, over half of caregivers in Cohort 2 with follow-up assessments had improved levels of burden, stress, and depression,
- Caregivers in Cohorts 2 and 4 also had improved financial strain.
- Caregivers in Cohorts 2, 3, and 4 had less negative impacts on ability to work among employed caregivers.
- Most caregivers found the enrollment and reimbursement processes Somewhat Easy or Very Easy to navigate.
- Caregivers said the respite and other services available through the program relieved stress and anxiety, helped them care for themselves, and enabled them to be better caregivers.

To meet the requirements of the evaluation, we report on different groupings of Respite for ME Grants caregivers (Table 11). We report demographic characteristics and measures of stress, burden, and impacts on working for all caregivers to understand if the pilot reached the target population. Not all who enrolled ultimately used services, and not all who used services completed follow-up assessments. The pre-post analysis of stress, burden, and impacts on work are reported only for those who had follow-up assessments and by cohort group.

Table 11 Caregivers in each analysis cohort

Cohort	Enrolled	Used Services	Had a Follow-Up
Cohort 1	159	102	65
Cohort 2	442	358	222
Cohort 3	121	121	101
Cohort 4	119	118	99
Total	**841**	**699**	**487**

Note: Follow-up groups include anyone from year one and/or year two who received at least one follow-up score.

Program Efficiency Results

Summary Findings

- It took AAAs about two weeks to complete the enrollment process, including receiving the attestation of financial hardship due to COVID-19 from caregivers.
- Many enrollees started receiving services several days after being enrolled.
- Caregivers all over Maine enrolled in the Respite for ME Grants program.
- Caregivers from Cumberland and Kennebec Counites made up one-third (33%) of caregivers in the program.

Statewide, 841 unique caregivers enrolled in the Respite for ME Grants pilot program between 10/1/2022 and 7/31/2024, the first twenty-two months of implementation, though not all used services. This section examines this group of caregivers to evaluate program efficiency measures.

Enrollment Process Timeframes

In Year 1, it took an average of 12 days after the application to the program was received to confirm eligibility. This dropped to 11 days in Year 2. Participants were required to submit the completed application form and the Attestation or Proof of Hardship form to their AAA before the AAA could send the eligibility confirmation letter and complete the enrollment process. Once caregivers were enrolled, they completed the TCARE® assessment with their AAA Family Caregiver Specialist. In Year 1, caregivers received Respite for ME Grants services on average 32 days after the TCARE® assessment. This dropped to 21 days in Year 2. Although most caregivers who used services were able to do so within one month of enrollment, others accessed services two months or more after they enrolled (Table 12). Caregivers may not have been able to find the services they needed, or they may have been saving their access to the funds for a future purchase later in the year.

Table 12 Most caregivers accessed Respite for ME Grants services within one month of enrollment.

Program Efficiency Measures	
YEAR 1	
Average days between application and eligibility confirmation	12
Average days between eligibility confirmation and receipt of services	32
Percent of participants receiving services after enrollment by time (n=339)	
0-10 days	50%
11-20 days	14%
21-30 days	6%

Program Efficiency Measures	
31-40 days	6%
41-50 days	6%
51-60 days	1%
60+ days	17%
YEAR 2	
Average days between application and eligibility confirmation	11
Average days between eligibility confirmation and receipt of services	21
Percent of participants receiving services after enrollment by time (n=580)	
0-10 days	57%
11-20 days	16%
21-30 days	9%
31-40 days	4%
41-50 days	3%
51-60 days	2%
60+ days	10%

Note: Year 1 includes 339 caregivers who used services in the first year of implementation, not all who enrolled. Year 2 includes 580 caregivers who used services in the first ten months of year two of implementation, not all who enrolled.

Demographics of Participants

Summary Findings

- Most caregivers enrolled because it was the only respite program available to them.
- Most caregivers were women and were over 60 years old.
- One-third of caregivers said they had fair or poor health status at enrollment.
- Most caregivers had high levels of burden at enrollment and said caregiving was Somewhat or Very Much a financial strain.

To help understand who chose to enroll in the Respite for ME Grants program, this section presents caregiver characteristics based on the 841 caregivers who were enrolled in the program at some point between 10/1/22 and 7/31/24.

Enrollment by AAA

By AAA, Spectrum Generations had the highest number of caregivers, followed by Southern Maine Area Agency (Table 13).

Table 13 Enrollment by AAA from October 1, 2022, to July 31, 2024.

Area Agency on Aging	Enrolled
Aroostook Area Agency on Aging	105
Eastern Area Agency on Aging	125
Seniors Plus	66
Southern Maine Area Agency	261
Spectrum Generations	284
Total	**841**

Enrollment by County

Participants in Aroostook County, Cumberland County, Kennebec County, York County made up over half of pilot participants (Table 14).

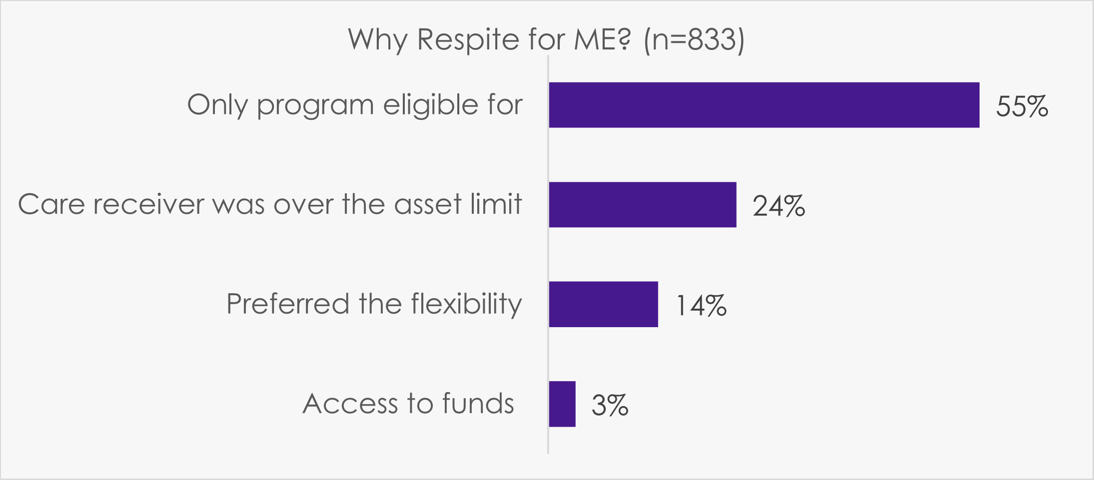
Table 14 Cumberland County had the most pilot caregivers.

County	Number enrolled	Percent
Androscoggin	33	4%
Aroostook	104	12%
Cumberland	144	17%
Franklin	14	2%
Hancock	30	4%
Kennebec	136	16%
Knox	26	3%
Lincoln	29	3%
Oxford	20	2%
Penobscot	82	10%
Piscataquis	2	0%
Sagadahoc	12	1%
Somerset	35	4%
Waldo	29	3%
Washington	9	1%
York	136	16%

Why Respite for ME?

At enrollment, when asked why they chose to enroll in the Respite for ME Grants program, a majority of caregivers across both years said it was the only program for which they were eligible (Figure 10). This finding indicates that the pilot was able to meet its goal of expanding eligibility for respite services to a broader population than what is allowed under State-funded Respite or FCSP. Approximately one-quarter of caregivers enrolled in Respite for ME Grants because their care recipient had too many assets to qualify for State-funded Respite. Although not shown on Figure 10, twenty-two (5%) caregivers participating in Year 1 chose Respite for ME Grants for the flexibility of services covered. While this is a small group, it is noteworthy because the Respite for ME Grants fund amount was less than half of the State-funded Respite benefit at the time. In Year 2, 91 (21%) caregivers said they enrolled because of the flexibility and options available in the Respite for ME Grants program. These findings indicate that services other than respite are of value for caregivers.

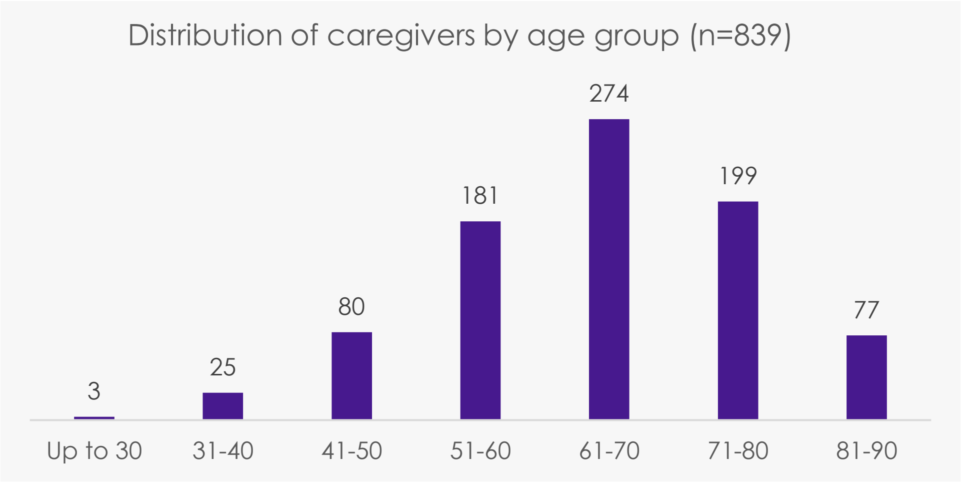
Figure 10 Participants chose Respite for ME Grants because it was the only program they were eligible for across Year 1 and Year 2.



Demographics

The average age of caregivers was 65 years old. Over two-thirds (68%) of caregivers were 60 or older, with the largest group being between 61 and 70 years old (Figure 11). A complete list of demographic characteristics can be found in Appendix C.

Figure 11 The largest group of caregivers was 61-70 years old.



Other notable characteristics of caregivers:

- 76% identified as women.
- 20% had annual household income under $25,000, and another 52% had incomes between $25,000 and $50,000.
- 25% had a high school diploma/GED-level of education.
- 75% were married or had domestic partners.
- 34% had fair or poor health status.
- 41% were working at some level.
- 15% had care recipients who had behavioral issues.

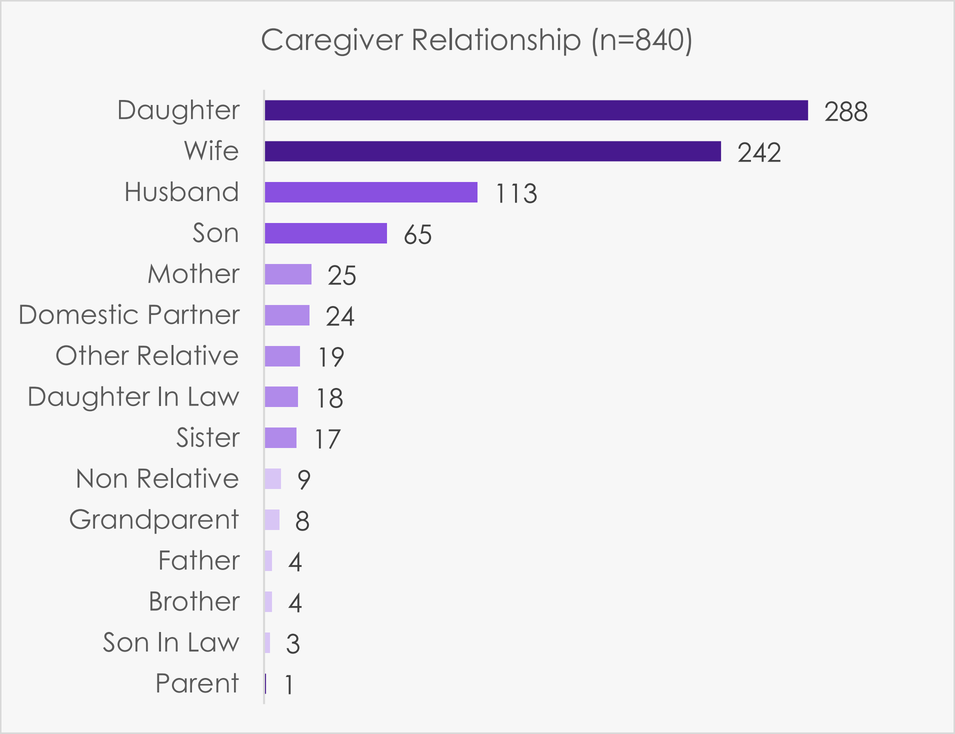
Demographics of Participants on the Waitlist

Six out of seven waitlisted caregivers were from the Aroostook AAA. Four of these were on the waitlist from mid-November 2023 through January 24, 2024. Of all waitlisted caregivers, 71% were female, 29% male. All identified as non-Hispanic and White. All waitlist participants made less than $50,000 in income. The average age was 60. The average time on the waitlist was 57 days. Five of the seven waitlist participants were removed from the waitlist when the Respite for ME Grants funds became available. Two participants voluntarily removed themselves from the waitlist. The waitlist was cleared by August 2, 2024.

Caregiver Relationship

The relationship of caregivers to their care recipients varied, but a majority (530, 63%) were either daughters or wives of the care recipient (Figure 12).

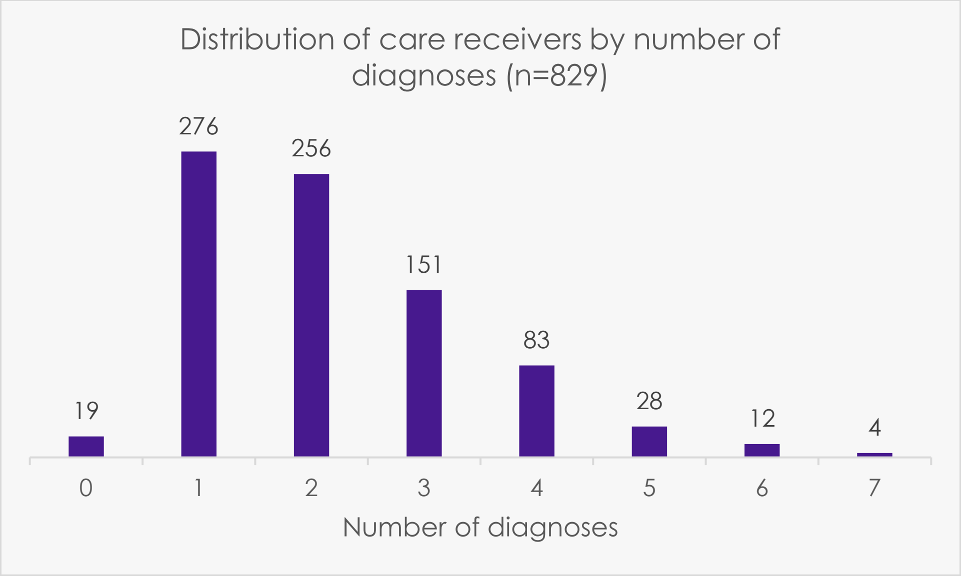
Figure 12 Most caregivers were daughters or wives of their care recipient.



Care recipient Diagnoses

Over half (532, 63%) of the 829 caregivers who provided care recipient diagnoses reported their care recipients had one or two diagnoses. Over one-third (278, (34%)) had three or more diagnoses (Figure 13).

Figure 13 Most care recipients had one or two diagnoses.



As described earlier, a key difference between the Respite for ME Grants pilot and the State-funded Respite program is the expanded eligibility beyond care recipients with a physician's written diagnosis of Alzheimer's disease or related dementia (ADRD). Although the Respite for ME Grants program did not collect medical records from caregivers, the evaluation collected care receiver diagnosis information as self-reported by caregivers. Sixty-three percent of caregivers said their care recipient had ADRD or memory issues, 29% had heart disease, and 18% had cancer.

TCARE® Measures of Burden at Enrollment

At enrollment, the initial total TCARE® score[**] of the 399[††] caregivers who enrolled in Year One (Cohorts 1, 3, 4) ranged from 29[‡‡] to 92, and the mean score was 57.4 (SD +/- 13.1). The initial total TCARE® score of the 442 caregivers who enrolled only in Year Two (Cohort 2) ranged from 23 to 92 and had a mean score of 61.9 (SD+/- 12.5).

Table 15 shows the percentage distribution of initial TCARE® scores ranked Low, Medium, and High across the different domains for all caregivers enrolled in the program across all cohorts and years of participation. Most caregivers entered the pilot with High levels of burden in overall stress (Stress Burden), caregiving responsibilities (Objective Burden), and having to fulfill responsibilities that are not in line with their own personal boundaries and norms (Identity Discrepancy). Many caregivers also had High levels of burden in their relationship with their care recipient (Relationship) and symptoms of depression (Depression).

Table 15 Distribution of caregivers with Low, Medium, and High initial TCARE® measures of burden across all cohorts and all years.

	Relationship	Stress	Objective	Depression	Identity Discrepancy
Low	0-11%	2-4%	0-3%	11-20%	2-3%
Medium	35-48%	13-18%	12-19%	23-35%	8-10%
High	43-54%	79-88%	78-88%	50-66%	87-90%

[**] Initial total TCARE® score is the sum of Relationship Burden, Stress Burden, Objective Burden, Depression, and Identity Discrepancy scores.

[††] Six of the 405 caregivers who enrolled in Year 1 never used services before re-enrolling in Year 2. They were assigned to Cohort 2 for purposes of the evaluation analysis.

[‡‡] One participant in Cohort 3 had a TCARE® score of zero in Year 1, an outlier for the cohort.

Initial TCARE® scores were higher for caregivers in both years whose care receiver had behavioral issues than those who did not. Caregivers whose care receiver had behavioral issues had an average initial score of 60.1 compared to 56.1 in Year 1 and 65.3 compared to 58.6 in Year 2 (Year 1 p=.005, Year 2 p<.001).

Mean initial total TCARE® scores were lower for caregivers in Year 1 who said caregiving was Not at All a financial strain compared to those who said it was Somewhat (p=.004) or Very Much (p=.012). The effect size was small, indicating it explained little of the variation. The same relationship was not found in Year 2.

Caregivers in Year 2 who said caregiving impacted their ability to work or their job performance had higher initial TCARE® scores than those who did not (p=.023 and p=.005, respectively). Again, the effect sizes were quite small, and the same relationships were not found in Year 1.

There were some significant findings in the relationship between initial TCARE® score and caregivers at different education levels and with different marital statuses. However, unequal group sizes in these analyses limit the robustness of these findings, and they are not presented in this report. There were no other significant findings to explain TCARE® score variation by caregiver or care receiver characteristics.

Intent to Place the Care Recipient

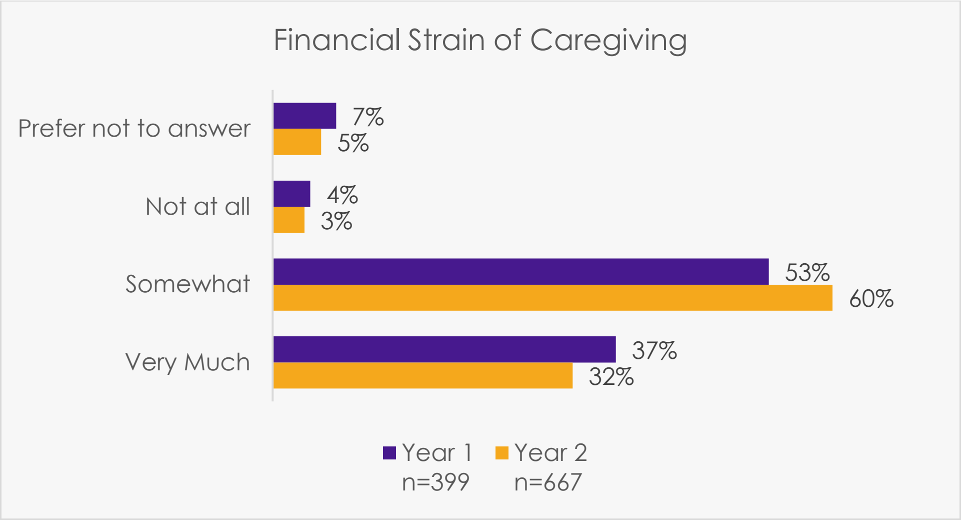
Eighty-six percent of caregivers (340) in Year 1 and 88% (600) in Year 2 initially indicated they were not intending to place their care recipient in an alternate setting given their current condition or if their condition worsened. Pearson's chi-square tests showed a significant positive correlation between the intent to place the care recipient and whether the care recipient had behavioral issues (Year 1 p=.002, Year 2 p<.001). The effect sizes in both years were small. Little of the intent to place a care receiver was explained by their having behavioral issues, and other factors may influence that decision.

Chi-square tests revealed no significant associations between caregiver intent to place their care recipient and caregiver age, gender, race, ethnicity, sexual orientation, marital status, household size, education level, initial health status, income group, impact of caregiving on ability to work at the caregiver's desired level or hours, or impact of caregiving on job performance. A slight association was found in Year 2 with children/children-in-law being more likely to say they intended to place their care recipient (*p*=.032), but the effect size was very small, indicating little of the intent to place can be explained by the relationship between the caregiver and care receiver.

Financial Strain of Caregiving

Participants were asked how much caregiving presented a financial strain. Most caregivers in both Year 1 and Year 2 said caregiving was somewhat or very much a financial strain (Figure 14).

Figure 14 Caregiving was a financial strain for most caregivers in both years of the pilot.



The initial financial strain of caregiving was associated with the impact of caregiving on the caregiver's ability to work in the prior six months for participants in both pilot years (*p*<.001). The effect size was moderate in both years but stronger in Year 1. A higher proportion of caregivers saying caregiving had impacted their ability to work their desired hours (Year 1 47%, Year 2 43%) also said caregiving was Very Much a financial strain compared to those who did not have work impacts (Year 1 28%, Year 2 26%).

Findings on the relationship between initial financial strain and job performance were mixed. In Year 1, the impact of caregiving on job performance was associated with Very Much financial strain (41% of caregivers, p<.001). In Year 2, 35% of caregivers who said caregiving impacted their job performance also said it was Very Much a financial strain at enrollment, but the finding was not significant (*p*=.282).

Service Use

Summary Findings

- Respite was the most used service in both years, followed by Assistive Technology/Devices and Chore.
- A higher percentage of Respite for ME Grants participants used Home Modifications than those in State-funded Respite.
- About two-thirds of Respite for ME Grants participants in each year used services other than Respite, Assistive Technology/Devices, and Home Modifications.

Comparison to State-funded Respite

Table 16 shows the number of caregivers who used different services under the Respite for ME Grants pilot and State-funded Respite programs October 1, 2022-July 31, 2024). Most people using State-funded Respite used In-home Respite care, but about half of caregivers in Respite for ME grants used this type of service. Many Respite for ME Grants participants used Assistive Technology/Devices and Home Modifications, but relatively few State-funded Respite participants used these services.

Of note, in Year 1, 62 (18%) caregivers used home modifications/repairs under Respite for ME Grants, while only eleven (5%) used these services under State-funded Respite. In Year 2, 106 (18%) used home modification under Respite for ME Grants and 4 (3%) used home modification under State-funded Respite. This disparity likely reflects the $2,000-lifetime cap on this service under State-funded Respite. Respite for ME Grants does not have a lifetime cap. Two-thirds of Respite for ME Grants participants in Year 1 and 70% in Year 2 used services other than Respite, Assistive Technology/Devices, and Home Modifications.

Table 16 Respite for ME Grants and State-funded Respite Participants

	Respite for ME Grants Y1	State-funded Respite Y1	Respite for ME Grants* Y2*	State-funded Respite Y2*
Total participants who used services	353	211	580	127
Respite				
In-Home	165	177	281	113
Out-of-Home Day or Night	10	4	10	1
Adult Day Services	14	43	66	16

	Respite for ME Grants Y1	State-funded Respite Y1	Respite for ME Grants* Y2*	State-funded Respite Y2*
Respite Other	--	8	3	--
Assistive Technology/Devices	145	10	289	7
Home Modifications/Repair	62	11	106	4
Other Respite for ME Services	230	-	403	-
Cost	$343,912	$666,310	$1,380,566	$428,896
Cost of other services	$197,488	--	$590,742	--
Total Cost	**$541,399**	**$666,310**	**$1,971,308**	**$428,896**

*Preliminary data pending final reconciliation. Year 2 shows 10 months of data from 10/1/2023 - 7/31/2024.

Only 699 of the 841 enrolled caregivers used services during the first twenty-two months of implementation. Of the 143 enrolled caregivers who did not use services, 73% did not indicate why they chose not to use funds. Twelve percent reported that their care receiver had passed away, and 2% had their care receiver placed elsewhere. The remaining caregivers had various reasons, including opting out of using the service, not being able to be contacted, the care receiver receiving waiver services, or moving out of the area.

Table 17 Caregivers who used services by Area Agency on Aging*

Area Agency on Aging	Caregivers who Used Services
Aroostook Area Agency on Aging	89
Eastern Area Agency on Aging	102

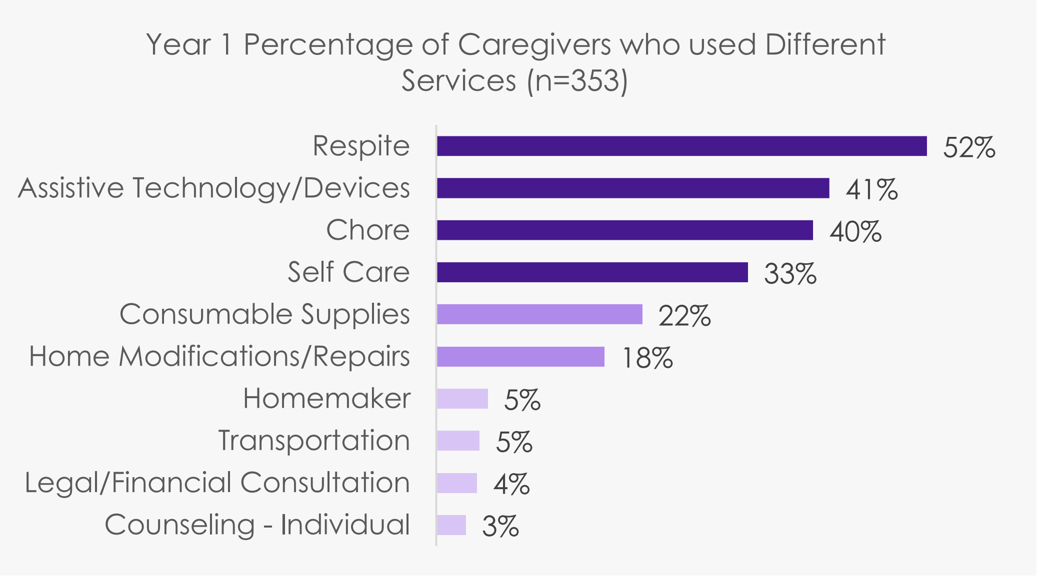
Area Agency on Aging	Caregivers who Used Services
Seniors Plus	48
Southern Maine Area Agency	231
Spectrum Generations	229
Total	**699**

*Based on 22 Months of data.

Most Used Services

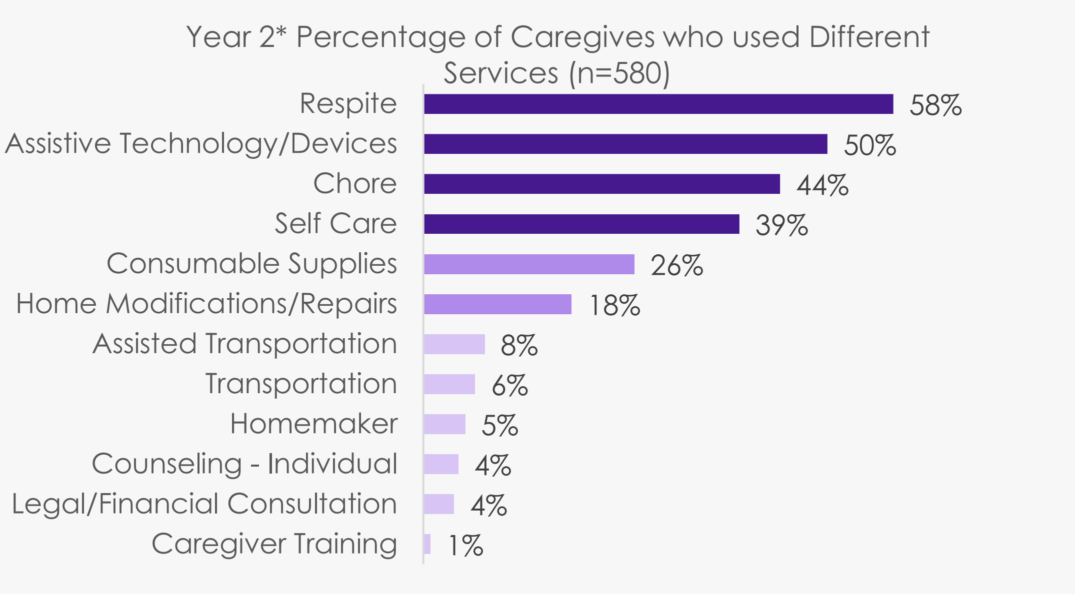
In Year 1, over half (52%) of caregivers used respite services, over one-third used assistive technology/devices (41%) or chore services (40%), and one-third (33%) used self-care (Figure 15). The percentage of users of different types of services varied by AAA, but none of the differences were significant (see Appendix C).

Figure 15 The most-used service types in Year 1 were Respite, Assistive Technology/ Devices, Chore, and Self Care.



In Year 2, over half (58%) of caregivers used respite services, half used assistive technology/devices (50%), almost half used chore services, and over one-third used self-care services (Figure 16). All service types showed an increase in Year 2, suggesting that more caregivers used more than one service.

Figure 16 Respite, Assistive Technology/ Devices, Chore, and Self Care were the most used services in Year 2 as well.



*Year 2 only shows 10 months of Service Use.

Table 18 shows the total dollars spent on Respite for ME Grants-funded services in Year 1 and Year 2- from October 1, 2022 - July 31, 2024. Overall spending increased by over $1.4 million in Year 2 as enrollment was higher and the dollar amount available per person increased by over $3,000. About one-third (36% in Year 1 and 30% in Year 2) of dollars spent under the pilot was for services other than respite, assistive technology, or home modifications—services not available under State-funded Respite like chores and self-care.

Table 18 Total cost of services used October 2022 - July 2024

Service	Year 1	Year 2*	Total
Respite	$191,243	$829,438	$1,020,681
Assistive Tech/Devices	$93,349	$366,032	$459,381
Chore	$89,574	$253,452	$343,026
Self-Care	$72,299	$208,272	$280,571
Home Modifications/Repair	$59,320	$185,095	$244,415
Consumable Supplies	$13,788	$31,923	$45,711
Legal/Financial Consultation	$7,116	$34,412	$41,528
Counseling - Individual	$5,352	$12,022	$17,374
Transportation	$5,802	$36,251	$42,053
Homemaker	$3,556	$10,429	$13,985
Caregiver Training	X	$3,492	$3,492
Total	**$541,399**	**$1,971,308**	**$2,512,707**

*Year 2 represents 10 months of service use. Year 2 total includes an additional $490 in unspecified services.

Spending varied by type of subservice. Spending on in-home respite day services was the highest. This service allows the caregiver to go to work, run errands, or address other needs while their care recipient remains in their home. Respite for ME Grants paid for Durable Medical Equipment such as lift chairs and other equipment not often covered by health insurance. Chore services such as yard work and housework helped caregivers with snow removal, lawn mowing, and home maintenance. Additionally, caregivers were able to purchase items for their health and wellness, including gym memberships and fitness classes (Table 19).

Table 19 Total costs of subservices, October 2022 - July 2024

Service Type	Year 1	Year 2*
Respite		
In-Home Respite Day	$167,686	$640,246
Adult Day Center	$11,571	$173,076
Out-of-home Day	$8,357	$5,144
Out-of-Home Overnight	$3,628	$9,203
Respite Other	X	$1,770
Assistive Devices/Technology		
Durable Medical Equipment	$38,051	$162,676
General Assistive Technology	$52,632	$195,975
Personal Emergency Response System	$2,666	$7,381
Chore		
Yardwork	$54,592	$126,143
Housework	$34,982	$126,714
Unspecified	X	$596
Self-Care		
Health and Wellness	$41,299	$137,657
Fitness equipment/items	$21,186	$44,067
Fitness class/membership	$9,800	$26,548
Consumable Supplies		
Incontinence Supplies	$13,611	$31,364
Other	$178	$559

Service Type	Year 1	Year 2*
Home Modifications/Repairs		
Accessibility	$50,521	$143,707
Health/Safety	$8,593	$36,217
Unspecified	$207	$5,171
Transportation		
Medical	$5,610	$32,804
Non-medical	$155	$3,447
Unspecified	$38	X

Note: Service Types Homemaker, Counseling Individual, Legal/Financial Consultation or Caregiver Training did not have subservices.
*Year 2 represents only 10 months of service use.

Outcomes

Summary Findings

- Measures of caregiver burden and depression, financial strain, and negative impacts of caregiving on caregiver ability to work and job performance improved, especially for those who participated only in Year 2.
- Although there were improvements, measures of caregiver burden and depression remained high for most caregivers.
- The percentage of caregivers in Cohorts 2 and 4 intending to place their care receiver in a facility increased.

To understand the impact that Respite for ME Grants had on caregiver burden, stress, and other outcome measures, this section focuses on the 487 participants who used services and had initial and follow-up TCARE® assessments.

Outcome Measure Analysis Cohort Groups

The outcome measure analysis is limited to caregivers in all cohorts who had an initial and at least one follow-up assessment across Year 1 and Year 2 (Table 20). The smallest cohort in this analysis, Cohort 1 (n=65), had access to $2,000 grants. The largest cohort, Cohort 2 (n=222) had access to $5,171. Cohort 3 (n=101) and Cohort 4 (n=99) had access to a combined total of $7,171 during their participation.

Table 20 Caregivers with initial and follow-up assessments by cohort

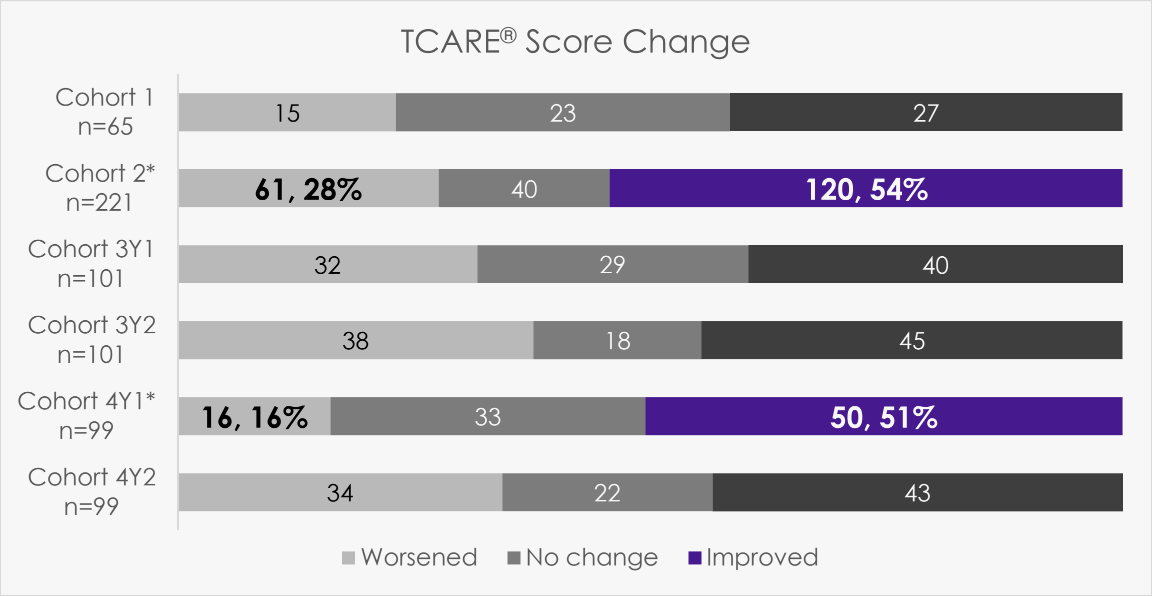
Cohort	Had a Follow-up Assessment
Cohort 1	65
Cohort 2	222
Cohort 3	101
Cohort 4	99
Total	**487**

Overall TCARE® Scores

To understand how caregiver stress and burden changed after participating in the Respite for ME Grants program, we examined the initial and follow-up assessment TCARE® scores for the different cohorts. Cohorts 1 and 2 each had one initial score and one follow-up score. Cohorts 3 and 4 had two pre-post assessments, one each year.

A Wilcoxon related-samples sign test indicating positive, negative, and no change in overall TCARE® score at the 90-day follow-up assessment showed that over half (120, 54%) of caregivers in Cohort 2 experienced a decrease (improvement) in TCARE® score (*p*<.001), and over half (50, 51%) caregivers Cohort 4 had a decrease in TCARE® score in their first year of participation (Cohort 4Y1) (*p*=.004). Sixty-one (28%) caregivers in Cohort 2 and 16 (16%) caregivers in Cohort 4Y1 had worsened mean TCARE® scores (*p*<.001, *p*=.002 respectively) (Figure 17).

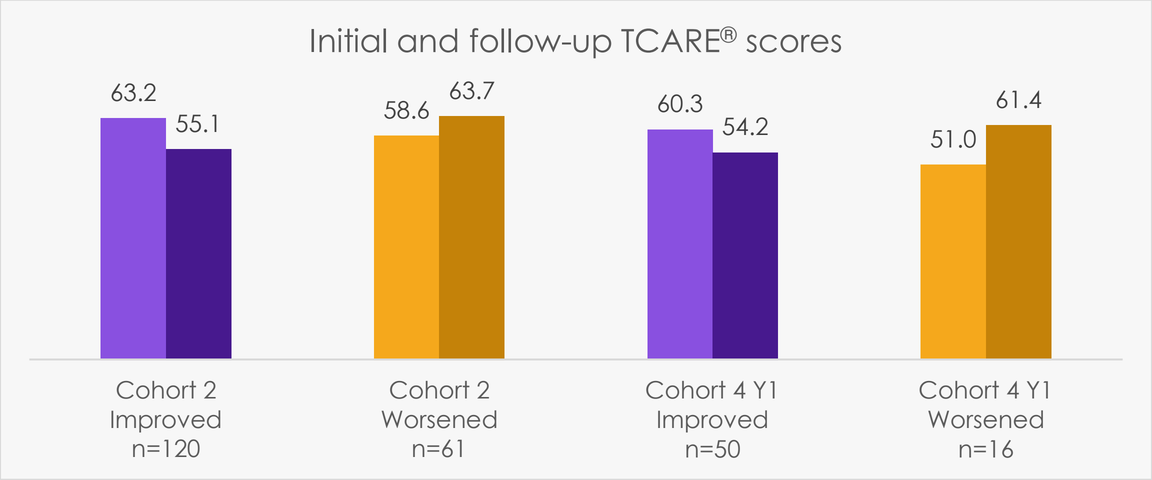
Figure 17 Many caregivers had improved TCARE® Scores over the pilot program, but others did not.



* Significant at the 0.05 level.

Figure 18 shows the average initial TCARE® scores among those with significant improvement or worsening scores.

Figure 18 Average initial TCARE® scores for Cohort 2 and Cohort 4Y1 who improved or worsened



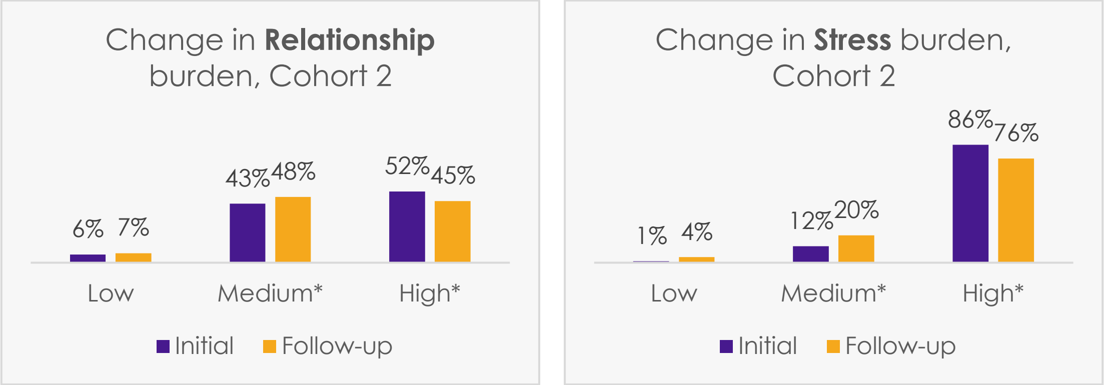
We conducted chi-square tests of association for the cohorts that had a significant positive change in TCARE® score, Cohort 2 and Cohort 4Y1, to examine the relationship between improvements in score and participant characteristics: age group, gender identity, education level, marital status, change in health status, household size, initial employment status, income group, relationship to the care recipient, and care recipient use of home-based care. There were no significant findings in this analysis.

There was an association between positive change in TCARE® score and follow-up financial strain, with caregivers being more likely to have improved scores if they had lower financial strain at follow-up (Cohort 2, *p*=.015, Cohort 4Y1 *p*=.004), and the effect sizes were moderately large in both cohorts. This indicates that the level of financial strain of caregiving at follow-up had a strong influence on whether TCARE® scores improved. However, there was no association between caregivers who had improved TCARE® scores **and** improved financial strain.

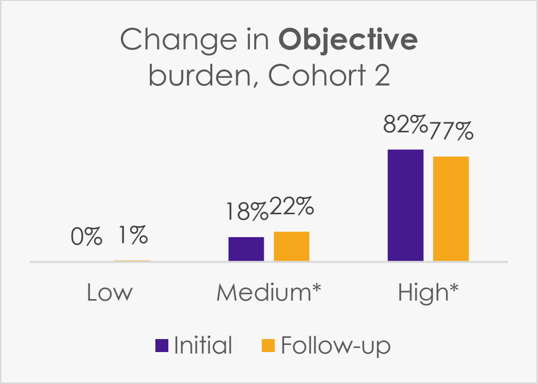
TCARE® Subscales of Burden

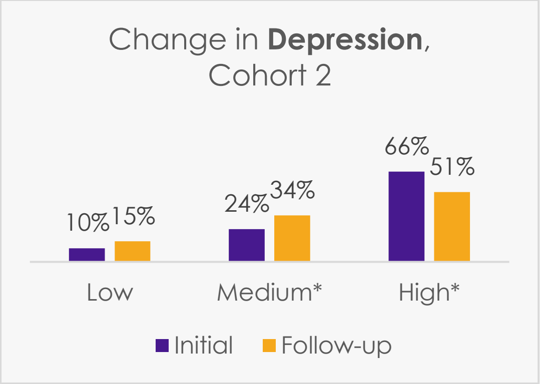
An examination of Cohort 2 and Cohort 4Y1 caregivers with low, medium, and high initial levels of TCARE® subscales of burden and at follow-up showed Cohort 2 improved in measures of Relationship, Stress, and Objective burdens as well as their Depression scores.[§§] In these measures, there was a decreased proportion of caregivers with high scores and an increased proportion of caregivers with medium scores at follow-up compared to their initial assessment (Figure 19) Cohort 4Y1 showed similar improvements only in caregivers' Stress burden. There were no significant findings in the other TCARE® measures or in the other cohorts.

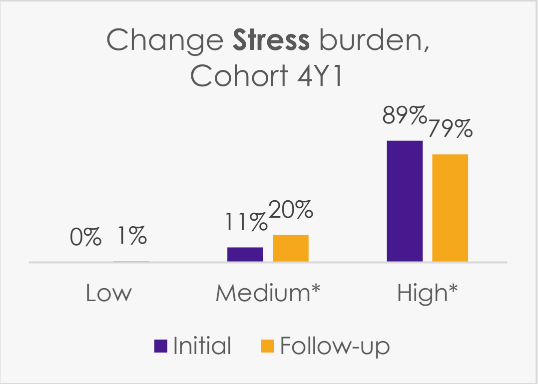
Figure 19 The proportion of participants with high Relationship, Stress, and Objective Burdens, and Depression Scores decreased.



[§§] McNemar paired sample proportions. See Appendix C for detailed findings.





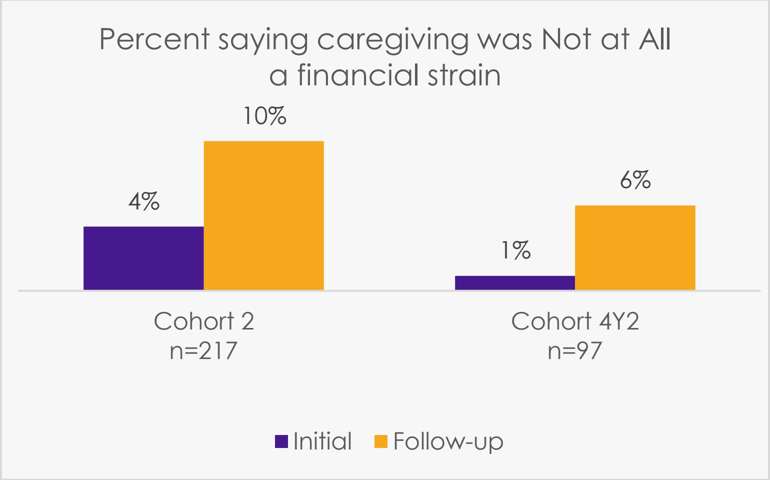


Note: Findings marked with * are significant at the 0.05 level.

Financial Strain and Negative Impact on Work or Job Performance

Of the Cohort 2 caregivers who answered follow-up questions about financial strain, the proportion indicating that caregiving was Very Much or Somewhat a financial strain at follow-up did not change significantly. However, the proportion of caregivers who said it was Not at All a financial strain increased from 4% to 10% (p=.009). Caregivers in Cohort 4 also experienced a similar increase in this measure from 1% to 6% (p=.025), but only in the second year of participation (Cohort 4Y2). The other cohorts had no significant changes in financial strain (Figure 20).

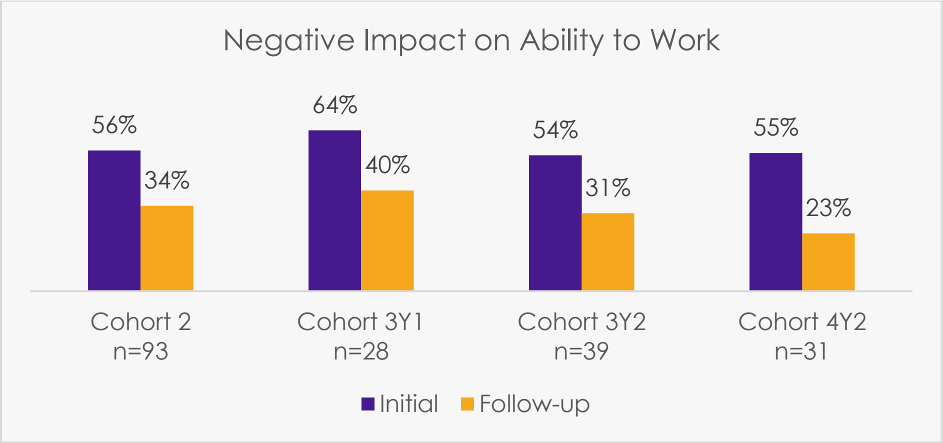
Figure 20 The percentage of caregivers who said caregiving was Not at All a financial strain at initial and follow-up



Note: Findings in both cohorts were significant at the 0.05 level.

Of the caregivers in Cohort 2 who answered follow-up questions about caregiving impacting their ability to work and job performance and who were employed full-time, part-time, unemployed, or retired but working part-time (i.e., not retired or homemaker), the proportion who said that caregiving had impacted their ability to work in the previous three months declined from 56% to 34% (*p*=.002). Caregivers in Cohort 3 who were not retired or homemakers also experienced decreases in the proportion saying caregiving impacted their ability to work in both years of participation (64% to 40% in Year 1, *p*=.020; 53% to 32% in Year 2 *p*=.038). Caregivers in Cohort 4Y2 who were not retired or homemakers experienced decreases in the proportion saying caregiving impacted their ability to work in Year 2 55% to 23% (*p*=.025). There was a small to medium effect size in these cohorts with Cohort 4Y2 having the largest at 0.68.

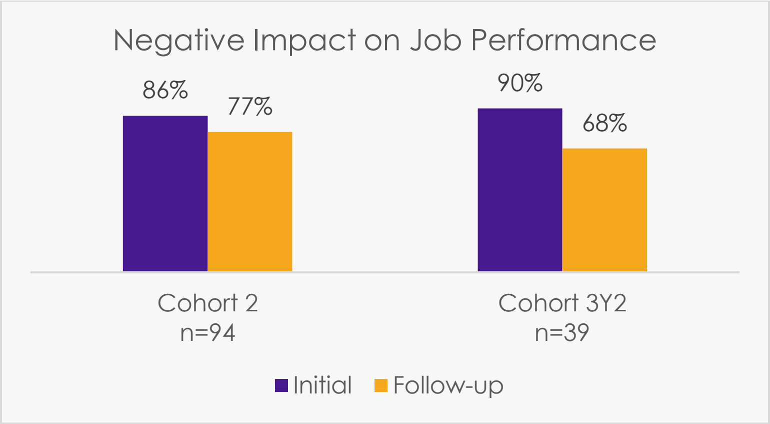
Figure 21 Caregivers in three of the cohorts improved in the impact of caregiving on ability to work.



Note: Decreases in the proportion of working participants who said caregiving negatively impacted their ability to work were significant at the 0.05 level.

Non-retired, non-homemaker caregivers in Cohort 2 and Cohort 3Y2 experienced a decrease in the proportion, saying caregiving negatively impacted their job performance from 86% to 77% (*p*=.039) in Cohort 2 and 90% to 67% (*p*=.007) in Cohort 3Y2.

Figure 22 Changes in negative impacts of caregiving on job performance.

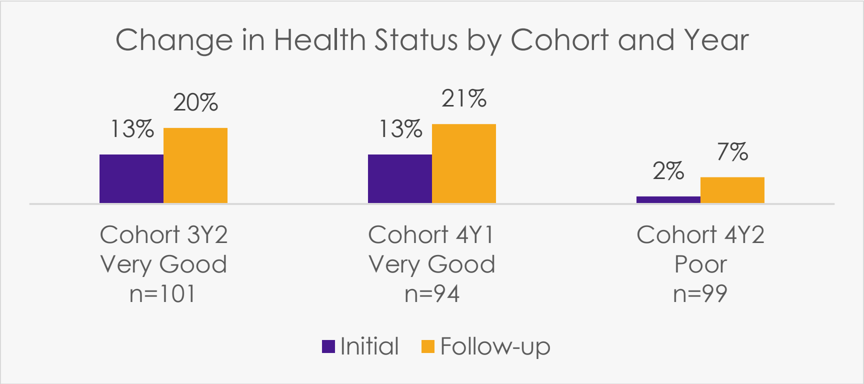


Note: Decreases in the proportion of working participants who said caregiving negatively impacted their job performance were significant at the 0.05 level.

Health Status

Findings on the health status of caregivers over the course of the pilot program were mixed with Cohort 1 and Cohort 2 showing no significant changes and caregivers in Cohort 3 and Cohort 4 showing positive impacts but in different years of participation (Figure 23). Some caregivers in Cohort 4 experienced declining health status in the second year of participation.

Figure 23 Cohorts 3 and 4 experienced improvements in health status in different years of participation.

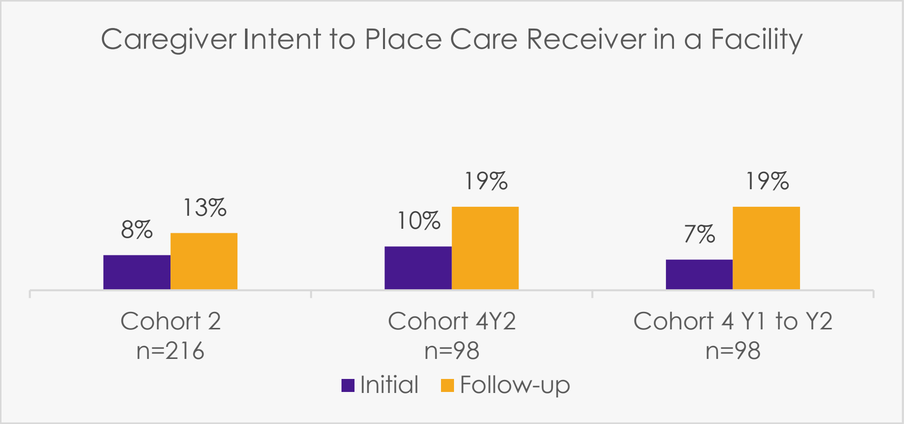


Note: Findings of changes in health status were significant at the 0.05 level.

Intent to Place

When asked about their intent to place their care recipient in a facility, the proportion of caregivers saying "yes" increased in Cohorts 2 and 4. The proportion of caregivers in Cohort 2 rose from 8% to 13% (*p*=.025). Caregivers in Cohort 4 experienced no significant change in the proportion intending to place their care receiver in a facility during their first year of participation. However, when they re-enrolled in the second year, the initial proportion had increased to 10%, which then rose to 19% at the second-year follow-up (*p*=.013). Across both years of participation, the proportion of caregivers intending to place their care receiver in a facility rose from 7% in Year 1 to 19% at their Year 2 follow-up assessment (*p*=.011). The advancing age and frailty of the care receiver could explain this increase. Due to the short duration of the pilot and lack of a control group, we cannot determine if participating in the Respite for ME Grants program averted or delayed any facility placements.

Figure 24 Change in intent to place



Note: Findings of change in the proportion of caregivers intending to place their care receiver in a facility were significant at the 0.05 level.

Lessons from Caregivers

Summary Findings

- The Respite for ME Grants program was very well-received by participants, and most found the enrollment and reimbursement processes Somewhat Easy or Very Easy to navigate.
- Caregivers appreciated the flexibility in what services were covered such as yard work, snow blowing, and durable medical equipment.
- Caregivers found the respite and other services available through the program valuable in relieving their stress and anxiety around meeting their care receiver’s needs while juggling their need to work and care for themselves.

Caregiver Survey and Interview Demographics

Respondents to the online survey had similar demographic characteristics as the overall Respite for ME Grants population. Nearly all caregivers in both the survey and the grant program identified as White (98% for both); most are female (81% survey; 76% program), over the age of 61 (66%; 65%), and married or in a domestic partnership (79%; 75%).

A similar percentage of respondents and pilot participants had high school or some college experience (51%, 52%), said they had Poor or Fair health status (28%; 30%), or said they were in Good health (54%, 53%). A lower percentage said they worked Full-Time (24%; 30%), and a higher percentage were Retired (47%; 42%).

Survey respondents had similar income levels as the pilot participants, with over half (54%, 52%) of each group having income between $25,000 and $49,000. A slightly lower percent of survey respondents had income below $25,000 (17%, 20%)

The demographics of the random sample of interviewees were generally representative of the respondents to the online survey and overall Respite for ME Grants participants. A higher percentage held bachelor and graduate degrees (57% compared to 43% in the survey and 35% in the grant population).

Table 21 shows the distribution of survey and interview participants across the Area Agencies on Aging.

Table 21 Survey and interview participants by Area Agency on Aging

Area Agencies on Aging	Survey respondents	Interviewees
Aroostook Area Agency on Aging	21 (11%)	5 (17%)

Area Agencies on Aging	Survey respondents	Interviewees
Eastern Area Agency on Aging	33 (17%)	3 (10%)
SeniorsPlus	12 (6%)	2 (7%)
Southern Maine Agency on Aging	71 (37%)	13 (43%)
Spectrum Generations	55 (29%)	7 (23%)
Total	**192**	**30**

Survey Results***

Most respondents (94%) reported not receiving any respite services before enrolling in the Respite for ME Grants pilot program, providing context for the benefits of this pilot program to those needing services.

Most (91%) respondents shared that the program was either Very Easy or Somewhat Easy to enroll. Of the four percent who shared that it was Very Difficult or Somewhat Difficult to enroll, reasons included trouble assembling paperwork (2%) or that the program was poorly publicized (1%).

Eighty percent (154) of respondents said that it was either Very Easy or Somewhat Easy to obtain services. Eight percent (15) indicated it was Somewhat or Very Difficult, citing a difficult and unclear reimbursement process, unavailable services, or a waitlist. Only one percent noted that the care recipient didn't want the services. Comments included the time-consuming burden of

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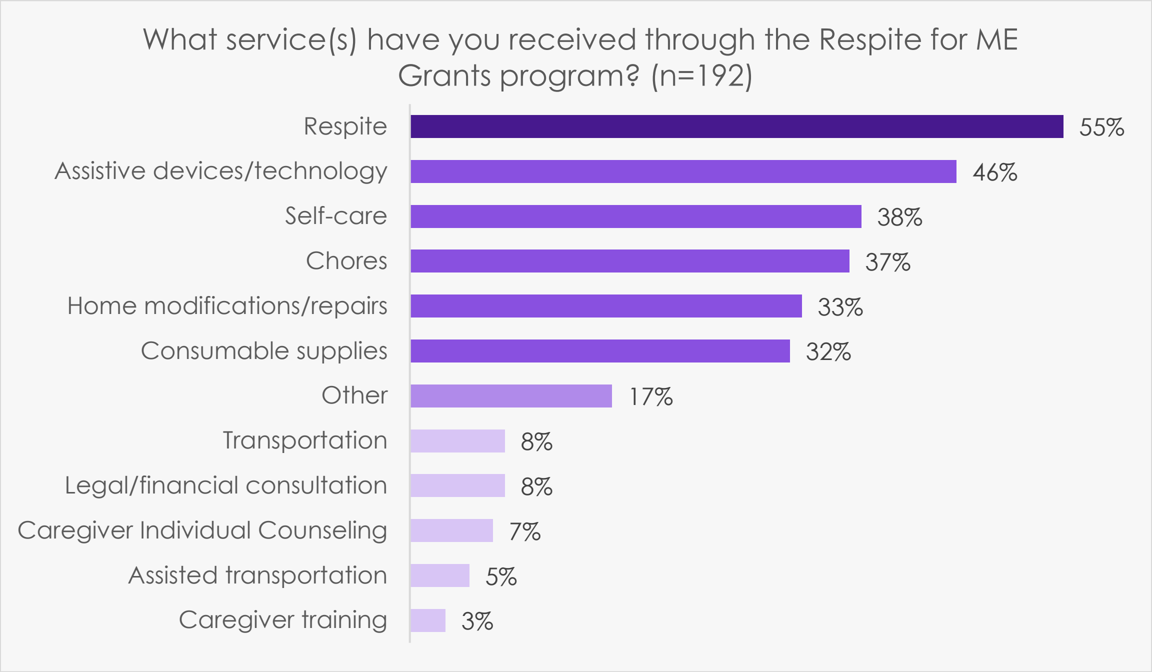
*** Quotes in this section are lightly edited for clarity and to protect anonymity.

completing the required paperwork and the lack of communication and feedback by program staff regarding errors in submitting receipts for reimbursement.

Figure 25 shows the most common services used by survey respondents, with Respite being the most used, followed by Assistive Devices and Self-Care.

Figure 25 Services use patterns of survey respondents reflect the same patterns among all Respite for ME Grants participants.



Respondents also had the opportunity to share additional information when selecting “Other” (17%). Some commented that funds were used for programs such as dental care, lawn care and snow plowing.

Nearly all survey respondents (97%) found the services Helpful or Very Helpful. Most survey respondents took advantage of the opportunity to write comments when asked what they liked best about the Respite for ME Grants program, with many stating that the program funded services they would otherwise not have been able to consider or afford. Survey participants noted that the program provided financial support and reimbursement for various self-care and caregiving-related expenses, helping ease the financial and emotional burdens they experienced.

> *"As a full-time caregiver, getting a little bit of time for myself is a difficult challenge. Your program has helped me keep my sanity."*

Program participants also appreciated the wide range of reimbursable services and the flexibility in how funds could be applied, such as compensating friends or neighbors for caregiving duties, and paying for items not covered by insurance. Program staff were praised for being helpful, knowledgeable, easy to contact, providing guidance, and promptly answering questions.

> *"Respite was so appreciated when I needed to leave him for appointments or grocery shopping. Also, many necessary medical items not covered by insurance were covered by Respite for ME."*

Several caregivers noted that the financial support of the Respite for ME Grants program allowed them to continue working or take much-needed breaks from caregiving.

> *"I work 40 hours a week, and I can't keep up with my own home and appointments. It's been wonderful to have someone help my mother with her chores and shopping for her needs. It's nice to be able to get reimbursed for these services rather than me giving up my own energy to do things for her and let my world be on hold."*

When asked what they like least about the Respite for ME Grants program, respondents expressed a few concerns, particularly about the paperwork required for reimbursement, with several wishing for an easier online submission process. There was also some confusion about what expenses qualify for reimbursement, with some seeing necessary items excluded. Others noted the slow turnaround time in getting reimbursement and the short window for submitting receipts. Several respondents faced difficulties managing upfront payments for services or items before getting reimbursed.

> *"It became a lot of work keeping up with the paperwork, and the money was coming from me, and I did not always get reimbursed in a timely fashion."*

Common themes about the program's funding limitations and discontinuation at the end of the pilot period highlighted the concern that caregivers felt they needed more support. Most (87%) respondents indicated they would be interested in participating in future caregiving respite programs. When asked to clarify their reasons for future participation further, respondents expressed overwhelming gratitude for the respite and financial support they received through Respite for ME Grants, emphasizing that it eased their burden of caregiving, provided much-needed financial and emotional relief, and helped make their responsibilities more manageable. They shared that balancing caregiving with personal and financial responsibilities can be overwhelming and described the challenges of caregiving as a 24/7 responsibility. Respite and emotional support were vital for their well-being.

Interview Results†††

Interview participants were asked how they heard about the Respite for ME Grants program, and many mentioned learning about the program through their local AAA office. Several said that a family member or friend mentioned it to them. Others discovered the program through marketing materials that included the Maine.gov website, newsletters, and social media. Several heard about the program through their medical provider.

Table 22 How participants heard about the pilot program

How did you hear about the Respite for ME Grants program?	Number	Percentage
AAA	10	33%
Family or Friend	6	20%
Marketing Materials	5	17%
Provider	5	17%
AARP	2	7%
Unsure	2	7%

Most key informants (75%) had not received caregiving or respite services before enrolling in Respite for ME Grants. Those who had used respite services before

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††† Quotes in this section are lightly edited for clarity and to protect anonymity.

enrolling had received them through local provider agencies, including the VA. Others said they relied on support offered by family and friends.

Table 23 Survey respondents had had prior respite care

Prior caregiving or respite care?	Number	Percentage
None	22	73%
Provider agency	4	13%
Family or friend	3	10%
Unsure	1	3%

Most Respite for ME Grants recipients we spoke with used the program funding in three major ways: Respite, Home Modifications, and Chores. This is a little different from the top services used in Year 1 and Year 2 by all program participants – Respite, Assistive Technology/Devices, and Chores. Six interviewees specifically spoke about their positive experiences with the flexibility to use the funding for various services for their loved ones and themselves. The ability to hire someone to come into their home, watch and/or care for their loved one, and do chores helped them as caregivers to find respite and do self-care without guilt.

> *"I've really never been able to focus on myself, and this grant helped me do that."*

“I would have never taken those classes. I would have never gone for a massage. I would not have done the self-care stuff. That’s huge for me. That’s my respite.

Home modifications such as ramps, handrails, and walk-in showers also helped improve access to and within the house, making it easier for the care recipient to be more independent.

Interviewees spoke of the difficulty in balancing work and care before the Respite for ME Grants program, with many having to either reduce their hours or quit work entirely to care for their loved ones. Five people specifically stated that caregiving responsibilities pulled them out of the workforce, but five others noted that the program enabled them to continue working. One interviewee said they did not have to use their sick time to transport their loved ones to the doctor or pick up prescriptions because of the Respite for ME Grants program. Several others noted the intangible benefit of reduction in stress and improved mental health that the program provided so that they could have the energy to be better caregivers.

“I’m able to hire care to come into the home and be with my mother while I’m at work, so I can be focused at my job and not be distracted.”

“The time spent with my parents is more visiting now, instead of me trying to [do all the chores, yard work, etc.]. Now I’m not as tired.”

> *“Being able to have Reiki or massage, so I'm able to go and get some tension relief... it gets me out of the house...all rested and refreshed and ready to go.”*

When asked how the financial support from the Respite for ME Grants program helped alleviate the pressures associated with caregiving, interviewees overwhelmingly noted the immense relief the Respite for ME Grants program provided in lifting both the financial and emotional burden of caregiving. They reiterated the program's help in paying for household chores, yard work, home modifications, and companion care—all things that they would not have been able to provide without the financial support from the program.

> *“This was very helpful, physically and emotionally, very much so and financially, obviously, to get reimbursed for things I felt like I couldn't really afford so I kept busting my butt to help them, and it was just very stressful.”*

> *“Financially, it's been a big help, it helps relieve the burden of worrying...because I have given up my job, my income sources are reduced. Now, I don’t have to put things off that I need. I don't have to go without it, which is a big deal for me, especially if it's my own mental health or something that needs to be taken care of at the house.”*

When asked if there were any things they would have changed about the Respite for ME Grants program, interviewees often said first how grateful they were for it. They appreciated the increase in funding this year and mentioned that they wished the program could continue or be offered longer.

> *"I thought it was extremely well run. Obviously, the larger amount of money the second year was a blessing."*

A common response centered around making sure others would be aware of this program (or one like it) since many initially learned about it serendipitously. At least ten interviewees cited outreach and communication processes could be improved.

> *"I guess just getting the word out there or knowing where to call or who to call."*

> *"I think the AAA did a phenomenal job in providing the resources to me. I don't think I would have known about Respite for ME otherwise. I've talked to people that are caretakers, they know nothing about it. So I don't know where that's advertised."*

A unique suggestion raised concerns about obtaining help with food since the care recipient felt a stigma around receiving Meals-on-Wheels.

Most of the interviewees spoke about the reimbursement process; some found it easy, but others found it confusing. Some thought the pre-populated sheets were very helpful, while others weren't sure how to fill out the forms so that the reimbursement would go through without revision. *"A little more clarity"* was a phrase used by several people and referred to the reimbursement process and the list of allowable services. One person stated that they didn't know they could purchase things for themselves (such as a massage), equating a comment from staff that caregivers are not usually paid to mean that they cannot be reimbursed for services for themselves. Many said the format of the list of covered services was not user-friendly. One person noted that they could not quickly find whether the item they wanted to purchase was covered, even when doing a “find word” search.

> *“I really do think it would be easier for the people looking at these receipts if it was spelled out much more clearly, saying this is what you can use it for.”*

Importantly, the 30-day reimbursement process was difficult for many who felt a cash-flow issue. Participants spoke of hesitancy to purchase services and supplies, not knowing if they would be reimbursed. A few noted that they reached out to the AAA for help filling out the forms so they would not be denied reimbursement. Others felt that the AAA wasn’t set up to facilitate electronic submissions for reimbursement and that providing proof of payments was not always easy. The delay between purchase, submission, and reimbursement was a cause of concern to several participants. Some noted that they had difficulty aligning the reimbursement check with their expenses, and there was no feedback on what was not reimbursed.

> *“When they send me the check, they do not say if they don't cover something, they don't tell me that, they just send a check.”*

> *“So, if I have respite care on the first, I have to wait till the end of the month to submit that and then it takes another two weeks to get that reimbursement. So it can be impactful.”*

> *“The turnaround time on reimbursement is pretty long. I think I usually wait over a month to get reimbursed.”*

Program Strengths

Overall, interviewees expressed the positive impact the Respite for ME Grants funding had on their ability to care for their loved ones at home. The program's strengths included the variety in the types of services, the flexibility in what was allowed to be reimbursed, and, to a certain extent, the reimbursement process. Recipients could use the funding for home modifications such as ramps and handrails, monitoring systems to ensure their safety, and personal and medical supplies. Caregivers were delighted with funding for respite services and self-care, with many taking advantage of a day at the spa, a massage, or mini getaways.

> *“It has given me a new perspective on caring for others in self-care. I think I'm happier and I feel more valued as a caregiver.”*

Areas for Improvement

Several interviewees noted that the reimbursement process was not always straightforward or timely. Many had questions and concerns about the appropriate process for managing their purchases and receipts and the timing of submissions and subsequent reimbursement. These concerns resulted in frustration, especially when there was a lack of communication and feedback. Suggestions for improvement included streamlining the process, providing clarity in written and verbal instructions, and making the submission process user-friendly (e.g., interactive PDF forms).

Most interviewees wanted to be sure that a program like this gets wide dissemination; they felt grateful for learning about it but didn’t want others to have to stumble upon it as they did. Suggestions for improvement also include more targeted outreach.

Discussion

Highlights

- The Respite for ME Grants pilot reached caregivers who had high levels of burden and experienced financial strain due to caregiving.
- Respite for ME Grants was often the only program available to enrolled caregivers. However, 14% of enrollees chose the program because of the flexibility in what the funds could be used for.
- The largest improvements were in decreased proportions of caregivers saying that caregiving impacted their ability to work.
- Caregiver feedback showed that Respite for ME Grants meaningfully impacted their physical, mental, and emotional well-being and made them feel valued.

Program efficiency measures and feedback from caregivers showed that caregivers who wanted to participate and were eligible were able to enroll and begin receiving services within a few weeks. The length of time between a caregiver's application and eligibility confirmation by the AAA was largely impacted by how quickly caregivers submitted the required paperwork. Caregivers often started receiving services within one month of enrollment. The reimbursement process was confusing and time-consuming for some caregivers, with some encountering cashflow problems while waiting for reimbursement for covered services. More clarity around the process and what services were covered could have alleviated some of these issues.

Over the implementation period, the Respite for ME Grants program reached its target population. After a slow start to enrollment in Year 1, enrollment in Year 2 increased rapidly, likely due to repeat caregivers and because the amount of funding was now similar to the state Respite program but with more flexibility in how to use the funds.

Respite for ME Grants was often the only respite program available to caregivers who enrolled, but some caregivers chose the program over others for the flexibility in what it reimbursed. This finding demonstrates that respite services are not the only services that have value for caregivers. Survey responses and key informant interviews demonstrated the positive impact that services such as self-care, fitness classes, and chore services can make in the lives of caregivers, reducing their stress and burden, allowing them to focus on their own needs and work life, and helping them feel valued.

Overall, TCARE® scores remained high on most measures for most caregivers, a common finding among studies of caregiving burden over time.[12] As the caregivers described in survey and interview responses, caregiving is physically, mentally, and emotionally draining. Although some caregivers experienced significant improvements in TCARE® measures, the limited nature of the funding and the ongoing nature of caregiving may curtail the ability of the grant support to change the measures of burden and stress meaningfully and with lasting effect.

The improvements in Cohort 2 in Relationship, Stress, and Objective burden and Depression scores, decreased financial strain, and negative impacts of caregiving on job performance, although statistically significant, were small. Most caregivers still had Medium or High TCARE® measure scores, said caregiving was Somewhat or Very Much a financial strain, and that it had negatively impacted their job performance.

The small size of the improvement in TCARE® outcome measures for Cohort 2 and the lack of significant findings in these measures for either Cohort 3 or Cohort 4 in the second year of the pilot may speak to the limits of lasting impacts of the grant program on caregiver burden and stress. Even with the increased funding in Year 2, participants of Cohort 3 and Cohort 4 did not have measurable improvements in their TCARE® scores in the second year. It is possible that over time, their caregiving burden and stress were impacted more by the ongoing and increasing needs of their care recipient. However, it should be noted that while there were no significant improvements, there were also no significant declines.

The largest improvements were in the decrease in the proportion of working caregivers in cohorts 2, 3, and 4, who said caregiving had negatively impacted their ability to work after receiving Respite for ME Grants services. The evaluation team could not analyze service use at the individual level, so we do not know if these caregivers used a particular service that helped improve their ability to work. However, qualitative findings from the survey and interview indicate that caregivers used respite services while were at work or used the funds to transport their care receiver to needed appointments or errands during the workday. Although outside of the scope of this evaluation, an assessment of the economic impact of caregivers' improved ability to work could inform policymakers about the costs and benefits of providing respite services to caregiving members of the workforce.

Overall, most caregivers enrolled in Respite for ME Grants had incomes less than $50,000, and the grant funds, especially in Year 2, may have represented an increase of over 10% in income to spend on caregiver and care receiver needs. This additional funding allowed many caregivers to purchase respite services, assistive technology, self-care, durable medical equipment, chore services, and other services that otherwise would likely have been out of reach.

The increases in the proportion of caregivers intending to place their care receiver in a facility if their condition worsened for caregivers in Cohort 4 speak to the increased frailty of the population over time. Cohort 4 had the longest period between the initial assessment in Year 1 and the final follow-up assessment in Year 2, potentially a twenty-two-month period. The provision of respite services, although beneficial for the caregiver, would likely have little impact on the care receiver's health over a long period. As the care receiver declined, there may have come a time when the caregiver could no longer provide care safely in the home, with or without grant funding. Across both pilot years, 47 care receivers were placed in a facility or began receiving Medicaid home and community-based waiver services. Forty-three care receivers passed away during the pilot program.

Limitations

This evaluation could not establish a causal relationship between Respite for ME Grants funds and changes in outcome measures as there was no control group of similar caregivers who did not receive the grant funds. Additionally, implementing TCARE® concurrently with Respite for ME Grants may have introduced confounding factors affecting the results. For example, caregivers' Depression scores may have decreased due to AAA Family Caregiver Staff assisting them in identifying their needs and obtaining services to address them. Because the two interventions were implemented simultaneously, it was impossible to separate the effects of one from the other.

The change in dollar amount available to caregivers from Year 1 to Year 2 presented a confounding factor in trying to compare caregivers who participated in the different years. The evaluation analysis plan required the creation of different cohorts to isolate caregivers who had similar grant amounts over similar periods of time. This created smaller groups for analysis and may have impacted the robustness evaluation, especially when looking at subgroups of participants by education level, income level, and other caregiver characteristics. For example, Cohort 1 had only 102 members who used services in the first year, and only 65 of whom had follow-up assessments.

It is possible that caregivers in Cohort 1 may not have found the program valuable enough to participate in a second year, and this could make them fundamentally different from Cohorts 3 and 4. It is also possible that changes in their care receiver's status may have impacted whether they had the same caregiving responsibilities. Without additional follow-up, the evaluation cannot explain why some caregivers chose not to re-enroll in the second year, even with the increased dollar amount.

Fidelity to the evaluation plan was inconsistent throughout implementation. It was anticipated that caregivers would enroll in Respite for ME Grants, go through the assessment and care planning process, obtain services in a timely way, submit receipts for the services, and be re-assessed 90 days following the first date of services. The evaluation was designed assuming that the impact level would be highest near the time services were received. However, because caregivers obtained their services and then submitted receipts for reimbursement, the AAAs could not know the date of the first service to start the 90-day clock for reassessment until the receipts were submitted.

During implementation, the AAAs noted that it was not uncommon for caregivers to hang on to their receipts and submit them all at once, well after the first day they started receiving services, sometimes months later. In these instances, the AAAs would attempt to schedule a follow-up assessment quickly. It is possible that the lag time between the date of the first service use and the eventual follow-up assessment could have diluted the impact of the Respite for ME Grants program. Once services were received and the funds were spent, if too long had passed, potential improvements in the caregiver’s burden may have reverted toward the baseline levels.

Conclusion

Caregiving is physically, emotionally, mentally, and financially challenging for many people, but respite and other services can ameliorate some of these challenges. The Respite for ME Grants program had a meaningful impact on participants' lives by providing financial assistance for services they identified to help relieve their burdens and stress. Feedback from participants reflected the importance of attending to caregivers' needs for respite and self-care in managing the physical, mental, and emotional stress of caregiving.

Improvements in TCARE® measures of caregiver burden, stress, and depression were most pronounced for caregivers in Cohort 2. However, even in this cohort, many, if not most, caregivers continued to have high levels of burden and stress at follow-up, in keeping with findings from other studies of caregiver burden.[16] Improvements in the negative impact of caregiving on working among employed caregivers was pronounced in Cohorts 2, 3, and 4. This finding, together with feedback from caregivers, provides evidence supporting the value of continuing the Respite for ME Grants program by aligning current State-funded Respite policies with the flexibility available in the pilot program.

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Appendices

Appendix A: Documentation

Respite for ME Grants: Process and Documentation

Eligibility and Application: WellSky

Caregiver initiates contact with ADRC/AAA (phone/email/other)

Caregiver connected to AAA's FCG Staff

Staff screens Caregiver for eligibility of Section 75, State-funded Respite, and Respite for ME Grants using the Family Caregiver Programs Assessment

Staff uploads dated Assessment to consumer record in WellSky via File Attachments regardless of program chosen

Caregiver eligible for and chooses the Respite for ME Grants pilot program

Caregiver completes Respite for ME Grants Application including COVID Attestation or Proof of Hardship

Staff uploads dated and signed Application to consumer record in WellSky via File Attachments

If AAA completes Application on phone with Caregiver, staff may write in “Completed on phone with (Name of Staff)” in the Caregiver Signature section and enter date completed.

Staff uploads dated and signed COVID Attestation, or Proof of Hardship documents, to consumer record in WellSky via File Attachments

Staff ensures all Caregiver and Care Recipient demographic and OAA required information from the Application is entered into the WellSky consumer records

Staff ensures Caregiver is enrolled in Caregiver Services Care Enrollment and Care Recipient enrolled in Access Services Care Enrollment

Staff enters appropriate Journals and Service Deliveries

- Staff will not move on from any steps until they are complete
- Staff will not move on to the TCARE® Assessment until the FCG Assessment, and Respite for ME Grants Application, including Attestation or Proof, are attached to the WellSky consumer record

- All forms will be attached to the WellSky consumer record within one business week from the date of completion or the date the document was received by the agency

Eligibility and Application: TCARE®

Staff has 60 days from the completion and receipt of the Application, including Attestation or Proof, to complete TCARE® Assessment and Care Plan

Staff and Caregiver complete TCARE® Full Assessment and Care Plan

Staff does not have to complete the TCARE® Screen separately as it is part of the Full Assessment

To save time- It is recommended that staff open the TCARE® Assessment and enter all demographic information for the Caregiver and Care Recipient using the Respite for ME Grants Application that is already completed and on file

If any information is missing, staff will complete in TCARE® and enter into WellSky

Staff prints and sends the Respite for ME Grants Eligibility Determination Letter and the TCARE® Care Plan to the Caregiver

Staff uploads the Eligibility Determination Letter to the WellSky consumer record

It is up to the agency's discretion to attach the TCARE® Care Plan to the WellSky consumer record

Staff enrolls Caregiver in the Respite for ME Care Enrollment

Date of care enrollment matches the date on the eligibility letter

Staff enters appropriate Journals and Service Deliveries

- Staff will not move on from any steps until they are complete
- All forms will be attached to the WellSky consumer record within one business week from the date of completion or the date the document was received by the agency

Receipts: WellSky

Caregiver provides receipts of paid Covered Services and request for reimbursement to AAA

AAA uploads receipts and request for reimbursement to WellSky consumer record

AAA enters Service Deliveries based on receipts

AAA follows internal process for reimbursing Caregiver

Staff enters appropriate Journals and Service Deliveries

- Receipts for Covered Services that were purchased, paid for, received, or occurred prior to the eligibility start date will not be accepted or reimbursed with Respite for ME Grants funds.
- ○ Care Enrollment Dates are NOT to be altered to fit receipts.
- Staff will not move on from any steps until they are complete
- All forms will be attached to the WellSky consumer record within one business week from the date of completion or the date the document was received by the agency

90 Day Follow Up: WellSky Assessment

AAA completes follow up assessment with Caregiver 90 days from first day money was spent

90 day follow up assessment is dated, completed, and uploaded to WellSky consumer record

- 90 day assessments may occur 5 business days prior to, or after, 90 days when necessary, based on Caregiver and AAA staff schedules.
- If Caregiver informs AAA that they are no longer eligible for program prior to 90 days, AAA does not have to complete 90-day assessment.
- AAA will record reason for and end dates in WellSky using the Respite for ME Care Enrollment screen
- If Caregiver informs the AAA on the day of, or during, the 90-day assessment, continue and complete assessment.

90 Day Follow Up: TCARE® Screen

TCARE® Screen is completed in TCARE® 90 days from first day money was spent

AAA can close out Caregiver in TCARE® once 90-day screen is complete, regardless of if all funds have been spent

- 90-day screens may occur 5 business days prior to, or after, 90 days when necessary based on Caregiver and AAA staff schedules.

- If Caregiver informs AAA that they are no longer eligible for program prior to 90 days, AAA does not have to complete 90-day assessment
- If Caregiver informs the AAA on the day of, or during, the 90-day screen, continue and complete screen.

Closing and Discharging Caregiver

Caregivers are completely discharged from Respite for ME when all the following are complete:

Year 1, $2000 spent; Year 2 $5,171 spent

Receipts and Service Deliveries attached to WellSky record

90-day WellSky assessment is complete and attached to WellSky record

90-day TCARE® screen is complete

Ensure Caregiver Respite for ME Care Enrollment is terminated in WellSky

Ensure Caregiver is closed out in TCARE®

- Caregiver may be closed prior to all steps being completed if Caregiver or Care Recipient are found to be ineligible.

Reminders:

- Caregiver = consumer
- Caregiver can only utilize one Respite funding source per FFY
- TCARE® protocol is required for all Caregivers who receive funding from Respite for ME Grants
- One $2000 grant per household 10/1/2022-9/30/2023; one $5,171 grant per household 10/1/2023-9/30/2024

Shoulder Season Caregivers

Applicable for Caregivers who meet the below scenarios during July 1, 2023, through December 31, 2023

1. Caregivers whose Year 1 initial TCARE Assessment and Care Plan occurs between August 1, 2023, and September 30, 2023
    a. Year 1 initial TCARE Assessment and Care Plan is valid for 90 calendar days
    b. Year 1 initial TCARE Assessment and Care Plan can be used for Year 2 initial TCARE Assessment and Care Plan *as long as* caregiver reapplies in their 90-calendar day window
        i. If caregiver wants to complete a new TCARE Assessment and Care Plan for Year 2, AAA must complete the process with caregiver

2. Caregivers whose Year 1 90-day follow up TCARE Assessment occurs between August 1, 2023, and September 30, 2023
    a. Year 1 90 day- follow up TCARE Assessment is valid for 90 calendar days
    b. Year 1 90 day- follow up TCARE Assessment can be used for Year 2 initial TCARE Assessment *as long as* caregiver reapplies in their 90-calendar day window
        i. If caregiver wants to complete a new TCARE Assessment and Care Plan for Year 2, AAA must complete the process with caregiver

3. Caregivers who make their initial Year 1 purchase between July 1, 2023, and September 30, 2023 *and* who enroll for Year 2 between October 1, 2023 and December 31, 2023
    a. Year 1 90-day follow up TCARE Assessment can be used for Year 2 initial TCARE Assessment
    b. If caregiver refuses a 90-day, follow up and wants to apply for Year 2
        i. Caregiver will have to complete a new initial TCARE Assessment and Care Plan prior to accessing any Year 2 funds
    c. If caregiver refuses a 90 day, follow up and has already applied for Year 2
        i. Caregiver will have to complete a new initial TCARE Assessment and Care Plan prior to accessing any remaining Year 2 funds

Appendix B: Data Definitions

Data element/Variable name	Working Definition
SESSION_DATE	The date when the Respite for ME Grants assessment is completed in WellSky (eligibility questions re: what kind of caregiver are you? What Covid-related economic harm did you experience? This date will be the "application date" required for the evaluation.
Date of eligibility	Date when eligibility confirmation letter is sent to caregiver detailing their eligibility for the pilot, what they can spend the funds on, times for spending the funds and submitting receipts, and other program rules.
Why Respite for ME Grants	For those who are eligible for State-funded Respite or Section 75, -- Why are you choosing Respite for ME Grants over 68 or 75, etc.? Flexibility There is a waitlist for 68 Other
Date of first service	Date when the caregiver paid for the first Respite for ME Grants service that they are requesting reimbursement for.
CARE_PROGRAM_NAME	Name of program serving the CG/CR pair (e.g., State-funded Respite, Respite for ME Grants)
COST	Total cost of service delivered (for State-funded Respite and Respite for ME Grants services)
UNITS	Number of units of service delivered (for Respite for ME Grants services)

Data element/Variable name	Working Definition
TCARE® Pre/Post Objective score	A negative psychological state that results from the perception that caregiving activities and responsibilities are infringing on other aspects of the caregiver's life, including time and energy to address other family obligations, leisure activities, and personal needs
TCARE® Pre/Post Stress score	A generalized form of negative affect that results from caregiving.
TCARE® Pre/Post Relationship score	Demands for care and attention over and above the level that the caregiver perceives is warranted by the care recipient's condition.
TCARE® Pre/Post Identity score	The affective psychological state that accrues when there is a disparity between the care activities in which a caregiver is engaging and those activities that would be consistent with his or her identity standard
TCARE® Pre/Post Depression score	Measured using a four point, 10-item short version of the Center for Epidemiological Studies-Depression (CES-D) scale capturing four underlying dimensions of depressive symptoms including dysphoria, somatic complaints, positive affect, and interpersonal distress
TCARE® Pre/Post Desire to Institutionalize	The caregiver's plan to place the care recipient in an alternate care setting and abdicate the role of primary caregiver.
SERVICE	Name of service associated with activity/referral
SERVICE_CATEGORY	Category of service associated with activity/referral
Month of institutionalization (if applicable)	Month the Care Recipient was institutionalized or moved to a higher level of care

Data element/Variable name	Working Definition
Impact of Caregiving on Ability to Work	As a result of your caregiving activities in the past six months, have you had to reduce your work hours or take a less demanding job; choose early retirement; or give up work entirely? Yes No
Impact of Caregiving on Job Performance	As a result of your caregiving activities in the past six months, have you gone in late, left early, taken sick time, vacation time, or personal time in order to care for your family member? Yes No
Financial Strain of Caregiving	How much of a financial strain is caregiving for you? Not at all Somewhat Very much Prefer not to answer
Impact of Caregiving on Ability to Work post Respite for ME Grants	As a result of your caregiving activities in the past 3 months, have you had to reduce your work hours or take a less demanding job; choose early retirement; or give up work entirely? Yes No
Impact of Caregiving on Job Performance post Respite for ME Grants	As a result of your caregiving activities in the past 3 months, have you gone in late, left early, taken sick time, vacation time, or personal time in order to care for your family member? Yes No
Impact of Respite for ME Grants on ability to work	Have the services you've received through Respite for ME Grants in the past 3 months improved your ability to work your regularly scheduled hours or allowed you to work more hours?

Data element/Variable name	Working Definition
	Yes No Don’t know/not sure
DOB	Date of birth
Gender Identity	
Sexual orientation	
ETHNICITY	
Race	
RES_ZIP	Zip code of residence
Date of death, if applicable	
MARITAL_STATUS	
RELATIONSHIP	Relationship of caregiver to consumer (care recipient)
IS_LIVES_ALONE	Does the consumer (the caregiver) live alone
VETERAN_STATUS	
HOUSEHOLD_SIZE	
Employment Status question from TCARE®	
Health status from TCARE®	
IS_PRIMARY_CAREGIVER	Is the caregiver the consumer’s primary caregiver? Yes No

Data element/Variable name	Working Definition
Care recipient use of home-based care from TCARE®	Yes/No
Care recipient behavioral issues from TCARE®	Yes/No
Care recipient diagnoses from TCARE®	
Previous receipt of respite services	Has the CR associated with the CG received State-funded Respite or 75 before? Yes No
Waitlist start date	Date when caregiver is put on a waitlist for Pilot
Waitlist end date	Date when caregiver is taken off the waitlist
TCARE® Pre-screen scores	Pre-screen score to show risk level
Waitlist end date reason	Reason why caregiver is taken off the waitlist Pilot funds became available Caregiver voluntarily dropped off Caregiver involuntarily dropped off (e.g., moved, died, CR died, CR institutionalization, etc.) Other

Appendix C: Detailed Findings

Table 24 Demographic Characteristics of Respite for ME Grants Participants by Cohort

Demographic Characteristics	Cohort 1 N=159	Cohort 2 N=440	Cohort 3 N=121	Cohort 4 N=119
AGE GROUPS				
Up to 30	1%	0.5%	0%	0%
31-40	4%	2%	2%	6%
41-50	10%	9%	9%	10%
51-60	23%	22%	26%	14%
61-70	31%	32%	37%	32%
71-80	21%	25%	20%	28%
81-90	11%	9%	6%	10%
GENDER IDENTITY				
Female	68%	76%	84%	79%
Male	32%	24%	16%	21%
SEXUAL ORIENTATION				
Straight or Heterosexual	98%	96%	96%	98%
Gay or Lesbian	2%	1%	4%	1%
No answer	0%	3%	0%	1%
RACE/ETHNICITY				
Non-Hispanic White	95%	98%	97%	97%
Hispanic White	1%	0.5%	1%	1%

Demographic Characteristics	Cohort 1 N=159	Cohort 2 N=440	Cohort 3 N=121	Cohort 4 N=119
American Indian or Alaska Native, Black or African American, Asian or Asian American	0.5%	2%	1%	3%
No answer	3%	0%	2%	0%
INCOME GROUP				
Under $15,000	10%	5%	8%	7%
$15,000-24,999	13%	11%	7%	16%
$25,000-34,999	42%	23%	34%	38%
$35,000-49,000	17%	25%	21%	17%
$50,000-$74,999	7%	16%	13%	13%
$75,000+	3%	14%	5%	8%
No answer	9%	6%	12%	2%
EDUCATION LEVEL				
Less than HS diploma	5%	4%	2%	2%
High school diploma/GED	26%	24%	24%	29%
Some college/Associate/Technical college	28%	34%	27%	32%
Bachelor's degree	11%	21%	21%	18%
Graduate degree	18%	15%	17%	17%
No answer	12%	2%	8%	3%
MARITAL STATUS				
Single	14%	15%	16%	13%
Married or Domestic Partner	74%	74%	74%	76%
Significant Other	2%	1%	0%	2%

Demographic Characteristics	Cohort 1 N=159	Cohort 2 N=440	Cohort 3 N=121	Cohort 4 N=119
Divorced	6%	7%	1%	4%
Widowed	4%	3%	1%	4%
No answer	1%	0%	16%	0%
HEALTH STATUS				
Very Poor	1%	0%	1%	0%
Poor	8%	5%	5%	3%
Fair	31%	23%	25%	27%
Good	48%	54%	50%	59%
Very Good	12%	18%	19%	12%
No answer	1%	0%	1%	0%
IS A VETERAN				
Yes	7%	5%	2%	3%
HOUSEHOLD SIZE (INCLUDING CAREGIVER)				
Alone	7%	5%	5%	3%
2	57%	71%	65%	60%
3	20%	16%	17%	24%
4	6%	5%	7%	4%
5+	9%	3%	5%	6%
No answer	1%	1%	1%	3%
INITIAL EMPLOYMENT STATUS				
Full Time	25%	26%	22%	18%
Part Time	8%	11%	10%	11%
Unemployed	15%	13%	15%	10%
Retired	38%	42%	40%	48%

Demographic Characteristics	Cohort 1 N=159	Cohort 2 N=440	Cohort 3 N=121	Cohort 4 N=119
Retired but working part time	8%	4%	11%	6%
Homemaker	4%	2%	2%	5%
Seasonally Employed	2%	1%	0%	3%
No answer	1%	2%	0%	18%
IS THE PRIMARY CAREGIVER				
Yes	93%	96%	96%	97%
CARE RECIPIENT USES HOME-BASED CARE				
Yes	11%	21%	28%	31%
CARE RECIPIENT HAS BEHAVIORAL ISSUES				
Yes	34%	41%	36%	24%
PRIOR RECEIPT OF RESPITE SERVICES				
Yes	1%	3%	1%	0%

Table 25 Chi-square test of association between caregiver characteristics, Year 1 and Year 2.

Demographic Characteristics	χ2(degrees of freedom)	2-tailed p-value	Cramer's V, Effect Size
INTENT TO PLACE			
Care Receiver has behavioral issues			
Year 1	9.311(1)	.002	.154

Demographic Characteristics	χ2(degrees of freedom)	2-tailed p-value	Cramer's V, Effect Size
Year 2	11.886(1)	<.001	.133
Caregiver relationship to care receiver, child or child-in-law			
Year 1	8.799(3)	.032	.114
FINANCIAL STRAIN			
Caregiving impacted ability to work			
Year 1	20.289(3)	<.001	.226
Year 2	23.879(3)	<.001	.188
Caregiving impacted job performance			
Year 1	16.822(3)	<.001	.206

Service Use Analysis

Table 26 Percentage of caregivers using the different types of services by AAA in Year 1 (n=353).

	Aroostook	Eastern	Seniors Plus	Southern Maine	Spectrum Generations
Respite	17%	23%	33%	22%	25%

	Aroostook	Eastern	Seniors Plus	Southern Maine	Spectrum Generations
Assisted Transportation	4%	0%	0%	2%	0%
Assistive Technology/Devices	20%	22%	18%	14%	21%
Chore	17%	18%	13%	19%	18%
Consumable Supplies	7%	13%	7%	10%	11%
Counseling Individual	1%	4%	0%	3%	0%
Home Modifications/Repairs	11%	6%	8%	6%	8%
Homemaker	5%	0%	2%	3%	2%
Legal/Financial	2%	0%	2%	4%	1%
Self-Care	11%	14%	17%	18%	14%
Transportation	5%	0%	0%	1%	0%

Table 27 Percentage of caregivers using the different types of services by AAA in Year 2 (October 1, 2023, to July 31, 2024) (n=580).

	Aroostook	Eastern	Seniors Plus	Southern Maine	Spectrum Generations
Respite	14%	22%	21%	27%	21%

	Aroostook	Eastern	Seniors Plus	Southern Maine	Spectrum Generations
Assisted Transportation	0%	4%	2%	4%	3%
Assistive Technology/Devices	21%	16%	20%	17%	22%
Caregiver Training	0%	0%	0%	1%	0%
Chore	18%	17%	19%	17%	15%
Consumable Supplies	9%	12%	13%	7%	12%
Counseling - Individual	0%	3%	3%	2%	1%
Home Modifications/Repairs	8%	9%	11%	4%	7%
Homemaker	4%	0%	1%	2%	2%
Legal/Financial	1%	1%	2%	2%	1%
Self-Care	14%	16%	7%	15%	16%
Transportation	12%	0%	2%	1%	0%

Significant Findings in Evaluation Measures

Table 28 Percentage Distribution of Participant Initial TCARE® Scores by Cohort with follow-ups and by Measure

	Relationship	Stress	Objective	Depression	Identity Discrepancy
COHORT 1, N=159					
High	52%	80%	80%	55%	87%
Medium	38%	18%	18%	42%	10%
Low	10%	2%	1%	1%	3%
COHORT 2, N=219					
High	52%	86%	82%	66%	90%
Medium	43%	12%	18%	24%	8%
Low	6%	1%	0%	10%	1%
COHORT 3, N=121 Y1(Y2)					
High	54% (50%)	79% (79%)	88% (83%)	56% (55%)	92% (90%)
Medium	35% (44%)	18% (17%)	12% (17%)	28% (31%)	4% (7%)
Low	11% (7%)	2% (4%)	0% (1%)	15% (13%)	3% (3%)
COHORT 4, N=121 Y1(Y2)					
High	47% (42%)	84% (79%)	83% (78%)	49% (50%)	88% (90%)
Medium	45% (49%)	15% (17%)	15% (19%)	31% (34%)	10% (8%)
Low	8% 9(%)	2% (3%)	3% (3%)	20% (17%)	3% (2%)

Table 29 Mean change in TCARE® scores for those who improved and worsened in Cohort 2 and Cohort 4, Year 1

Cohort	N	Mean change	CI	t test	df	Two-tailed p value	Effect size d
Cohort 2 who improved	120	-8.13	-9.36, -6.88	-13.052	119	<.001	1.20
Cohort 2 who worsened	61	5.13	4.09, 6.17	9.985	60	<.001	1.26
Cohort 4Y1 who improved	50	-6.04	-8.05, -4.03	-6.025	49	<.001	.852
Cohort 4Y1 who worsened	16	10.38	4.30, 6.44	3.644	15	.002	.911

Table 30 Positive change in TCARE® score related to lower levels of financial strain at follow-up.

Positive Change in TCARE® Score	χ2(degrees of freedom)	2-tailed p-value	Cramer's V, Effect Size
LOWER FOLLOW-UP FINANCIAL STRAIN			
Cohort 2	13.257(3)	.004	.245
Cohort 4Y1	10.489(3)	.015	.334

Table 31 Change in proportion of caregivers at Low, Medium, and High levels pre-post Respite for ME Grants participation, McNemar Paired Samples Proportion Test

COHORT 2	PRE	POST
RELATIONSHIP BURDEN, N=221		
Low	6%	7%
Medium z=-2.121, two-sided *p*=0.034	43%	48%
High z=2.694, two-sided *p*=.007	52%	45%
STRESS BURDEN, N=221		
Low	1%	4%
Medium z=-3.530, two-sided p<.001	12%	20%
High **z=4.131, two-sided p<.001**	86%	76%
OBJECTIVE BURDEN, N=220		
Low	0%	1%
Medium z=-2.041, two-sided *p*=.041.	18%	22%
High z=2.200, two-sided *p*=.014	82%	77%
DEPRESSION SCORE, N=221		
Low	10%	15%
Medium z=-2.840, two-sided *p*=.005.	24%	34%
High z=4.355, two-sided p<.001	66%	51%
IDENTITY DISCREPANCY, N=118, NO SIGNIFICANT FINDINGS		

COHORT 2	PRE	POST
Low	1%	1%
Medium	8%	10%
High	91%	89%

Table 32 The only significant findings for Cohort 4 were in Year 1, Stress Burden.

COHORT 4Y1	PRE	POST
STRESS BURDEN, N=96		
Low	0%	1%
Medium z=-2.398, two-sided *p*=0.21	11%	20%
High z=2.714, two-sided *p*=.007	89%	79%

Table 33 Changes in financial strain were significant only for those saying "Not at all" in Cohort 2 and Cohort 4 Year 2.

HOW MUCH IS CAREGIVING A FINANCIAL STRAIN?	PRE	POST
NOT AT ALL		
Cohort 2, n=217 z=-2.600, *p*=.009	4%	10%
Cohort 4Y2, n=97 z=-2.236, *p*=.025	1%	6%%

Table 34 Changes in caregiving impacts on work

Has caregiving impacted your ability to work in the previous three months?	**PRE**	**POST**
YES		
Cohort 2, n=93 z=3.162, *p*=.001, Cohen's h=.44	56%	34%
Cohort 3Y1, n=28 z=2.33, *p*=.020, Cohen's h=.51	64%	40%
Cohort 3Y2, n=39 z=2.138, *p*=.038, Cohen's h=.42	53%	32%
Cohort 4Y2, n=31 z=2.236, *p*=.023, Cohen's h=.68	55%	23%

Table 35 Changes in impact on job performance

Has caregiving impacted your job performance in the previous three months?	**PRE**	**POST**
YES		
Cohort 2, n=94 z=2.065, *p*=.039, Cohen's h=.25	86%	77%

Has caregiving impacted your job performance in the previous three months?	PRE	POST
Cohort 3Y2, n=39 z=2.714 *p*=.007, Cohen's h=.56	90%	68%

Table 36 Change in health status

Change in proportion of caregivers with different health status	INITIAL	FOLLOW-UP
Very good, Cohort 3Y2, n=101 z=2.111, *p*=.035	13%	20%
Very good, Cohort 4Y1, n=94 z=2.309, *p*=.021	13%	21%
Poor, Cohort 4Y2, n=99 z=-2.236, *p*=.025	2%	7%

Table 37 Change in intent to place

Are you thinking of placing your care receiver in a facility	INITIAL	FOLLOW-UP
YES		
Cohort 2, n=216 z=-2.236, *p*=.025	8%	13%
Cohort 4Y2, n=98 z=2.496, *p*=.013	10%	19%

Are you thinking of placing your care receiver in a facility	INITIAL	FOLLOW-UP
Cohort 4Y1-Y2, n=98 z=-2.558, *p*=.011	7%	19%

Appendix D: Caregiver Feedback

Survey and Interviews

Demographic Data

Most caregiver respondents identified as white (98%), female (81%), over the age of 61 (70%) and are married or in a domestic partnership (78%). Of the 188 survey respondents, most have pursued post-secondary education, and 54% have at least a high school diploma or some college. The survey population had a slightly higher number of female participants than the overall program.

Table 38 Demographics of survey respondents

Survey Demographics	Number	Percentage
AREA AGENCY ON AGING		
Aroostook Area Agency on Aging	21	11%
Eastern Area Agency on Aging	32	17%
SeniorsPlus	12	6%
Southern Maine Agency on Aging	71	37%
Spectrum Generations	54	28%
AGE GROUPS (N=190)		
31-40	5	3%
41-50	14	7%
51-60	37	20%

Survey Demographics	Number	Percentage
61-70	69	36%
71-80	51	27%
81-90	14	7%
GENDER IDENTITY		
Female	153	81%
Male	37	20%
EDUCATION		
Refused	4	2%
High School diploma/GED	36	19%
Some College/Assoc/Tech	65	35%
Bachelor's	53	28%
Graduate or above	28	15%
Didn't graduate high school	2	1%
RACE		
White	186	98%
Black	2	1%

Survey Demographics	Number	Percentage
American Indian or Alaska Native and Black or African American	2	1%
MARITAL STATUS		
Single	22	12%
Married or Domestic Partners	147	77%
Significant Other	4	2%
Divorced	11	6%
Widowed	4	2%
Legally Separated	2	1%
INITIAL HEALTH STATUS		
Very Poor	2	1%
Poor	10	5%
Fair	49	26%
Good	87	46%
Very Good	42	22%
FINANCIAL STRAIN OF CAREGIVING		
Not at all	8	4%

Survey Demographics	**Number**	**Percentage**
Somewhat	116	61%
Very Much	55	29%
Prefer not to answer	10	5%
CAREGIVING IMPACT ON ABILITY TO WORK		
Yes	65	34%
No	124	66%
CAREGIVING IMPACT ON JOB PERFORMANCE		
Yes	86	46%
No	103	55%

The majority identified as white (97%), female (77%), over the age of 61 (67%), and married or in a domestic partnership (80%). The educational backgrounds of the interviewees showed that the majority have pursued post-secondary education, and 44% have at least a high school diploma or some college.

The tables below describe the distribution of 30 key informant interview participants by demographics.

Table 39 Demographic characteristics of interviewees

KII Demographics	Percentage
AREA AGENCY ON AGING	
Aroostook	17%
Eastern	10%
SeniorsPlus	7%
Southern Maine Area Agency on Aging	43%
Spectrum Generations	23%
AGE GROUP	
41-50	3%
51-60	30%
61-70	40%
71-80	17%
81-90	10%
GENDER	
Female	77%

KII Demographics	Percentage
Male	23%
RACE	
White	97%
Black	3%
MARITAL STATUS	
Married or Domestic Partner	80%
Divorced	10%
Single	10%
EDUCATION	
HS Diploma/GED	7%
Some College/Assoc/Tech	37%
Bachelors	37%
Graduate or above	20%

Appendix E: Survey and Interview Documentation

Survey Email Drafts

Advanced Email Language from AAA

Subject: Advance Letter for Respite for ME Grants Program Survey

Dear Respite for ME Grants Caregiver:

Maine wants to improve services that support family caregivers. As a caregiver who has received Respite for ME Grants program, we would like to hear about your experience with the program.

In about a week, you will receive a short, emailed survey asking about your experience with the Respite for ME Grants program . The University of Southern Maine (USM) is conducting the survey on behalf of the State of Maine.

The survey can be completed by using an online link that will be included.

By completing this survey, you can play a key role in planning for services and programs that
support caregivers in Maine.

Hundreds of people like you will be asked to share their experiences and opinions about the Respite for ME Grants program. While the survey is completely voluntary (you don't have to do it), the findings will help the State understand what has worked well and what hasn't worked so well in Respite for ME Grants program.

Your individual responses are confidential and will be combined with the responses from everyone else who takes the survey. When you receive the survey, please participate and let us know about your experiences with the program.

If you have questions about the purpose of this survey, you may contact Catherine Slye at the Office of Aging and Disability Services, catherine.slye@maine.gov. The main office number is 207-287-9200.

Thank you in advance for your help. We look forward to hearing your thoughts and ideas for
improving services for caregivers in Maine.

Survey Introduction Language

If you are a caregiver and received Respite for ME Grants program funding, the State of Maine wants to hear from you.

This survey will provide feedback on the Respite for ME Grants program. By completing this survey, you can play a key role in planning for future respite services and programs.

This survey is being conducted by the University of Southern Maine (USM) on behalf of the State of Maine. This survey is completely voluntary, and you do not need to answer any question you do not want to. If you come to a question that you do not want to answer, just leave it blank and go on to the next question. Your individual responses are confidential and will be combined with the responses from everyone who took the survey. Your responses will not affect any services or benefits you or your care recipient receive.

- For questions about the purpose of this survey, please contact Catherine Slye at the Office of Aging and Disability Services, catherine.slye@maine.gov. The main office number is 207-287-9200.
- For technical questions about completing the survey online, contact Jennifer Pratt (jennifer.l.pratt@maine.edu or 207-699-6305}.

Survey Launch Email

Subject: Respite for ME Survey

Good day!

Maine wants to improve services that support family caregivers. As a caregiver who has received a Respite for ME Grants program, we would like to hear about your experience participating in the Respite for ME Grants program.

Below are answers to a few frequently asked questions.

Why am I getting this survey?
Our records indicate that you have participated and received funding in the Respite to ME program.

Do I have to fill it out?
This survey is completely voluntary (you do not have to do it), but your input will help the State of Maine plan for future respite services and programs.

How do I complete the survey?
- Complete the survey online here: {LINK}

What happens to the information I give you?
Your individual responses are confidential. Your responses will be added to responses from hundreds of individuals who have received Respite for ME grants.

What if I have questions?
- For questions about the purpose of this survey, please contact Catherine Slye at the Office of Aging and Disability Services, catherine.slye@maine.gov. The main office number is 207-287-9200.
- For technical questions about completing the survey online, contact Jennifer Pratt (jennifer.l.pratt@maine.edu or 207-699-6305}.

Thank you in advance for your help.

Survey Launch Reminder Email

Subject: Reminder: Respite for ME Survey

Good day!

Maine wants to improve services that support family caregivers. As a caregiver who has received a Respite for ME Grants program, we would like to hear about your experience participating in the Respite for ME Grants program. We really do want to hear from you! The survey will be available until {DATE}.

Why am I getting this survey?
Our records indicate that you have participated and received funding in the Respite to ME program.

Do I have to fill it out?
This survey is completely voluntary (you do not have to do it), but your input will help the State of Maine plan for future respite services and programs.

How do I complete the survey?

- Complete the survey online here: {LINK}
- If you need assistance in completing this survey, please call your Family Caregiver Support Specialist at your AAA for assistance.

What happens to the information I give you?
Your individual responses are confidential. Your responses will be added to responses from hundreds of individuals who have received Respite for ME Services.

What if I have questions?
- For questions about the purpose of this survey, Catherine Slye at the Office of Aging and Disability Services, catherine.slye@maine.gov. The main office number is 207-287-9200.
- For technical questions about completing the survey online, contact Jennifer Pratt (jennifer.l.pratt@maine.edu or 207-699-6305}.

Thank you in advance for your help.

Respite for ME Grants Program Feedback Evaluation

If you are a caregiver and received Respite for ME Grants program funding, the State of Maine wants to hear from you. This survey will provide feedback on the Respite for ME Grants program. By completing this survey, you can play a key role in planning for future respite services and programs. This survey is being conducted by the University of Southern Maine (USM) on behalf of the State of Maine. This survey is completely voluntary, and you do not need to answer any question you do not want to. If you come to a question that you do not want to answer, just leave it blank and go on to the next question. Your individual responses are confidential and will be combined with the responses from everyone who took the survey. Your responses will not affect any services or benefits you or your care recipient receive.

For questions about the purpose of this survey, please contact Catherine Slye at the Office of Aging and Disability Services, catherine.slye@maine.gov. The main office number is 207-287-9200.

For questions about completing the survey online, contact Jennifer Pratt (jennifer.l.pratt@maine.edu or 207-699- 6305).

1.) How easy was the process of enrolling into the Respite for ME program?
○ Very easy
○ Somewhat easy
○ Neither easy or difficult
○ Somewhat difficult
○ Very difficult

1a.) If Somewhat or Very difficult, why was it difficult? (check all that apply)
○ Financial hardship attestation form
○ Assembling paperwork
○ Eligibility
○ Other (please describe):

2.) How easy was it to obtain services reimbursed by the Respite for ME program?

○ Very easy
○ Somewhat easy
○ Neither easy or difficult
○ Somewhat difficult
○ Very difficult

2a.) If Somewhat or Very difficult, why was it difficult? (check all that apply)

☐ The service I wanted wasn't available in my area
☐ The service I wanted had a waitlist
☐ The person I cared for didn't want the service
☐ It was hard to know what was reimbursed
☐ The reimbursement process was difficult
☐ Other (please describe):

3.) Were you already getting respite services prior to enrolling in the Respite for ME program?

○ Yes
○ No
○ Unsure

4.) What have you liked best about the Respite for ME program? Please describe:

5.) What have you liked least about the Respite for ME program? Please describe:

6.) What service(s) have you received through the Respite for ME program? (check all that apply)

☐ Assisted transportation
☐ Assistive devices
☐ Assistive technology
☐ Caregiver Individual Counseling
☐ Caregiver training
☐ Chores
☐ Consumable supplies
☐ Home modifications/repairs
☐ Legal/financial consultation
☐ Respite
☐ Self-care

☐ Transportation
☐ Other (please describe):

7.) How helpful were the service(s) you received?
○ Very helpful
○ Helpful
○ Neutral
○ Unhelpful
○ Very unhelpful

8.) Would you be interested in participating in future caregiver respite programs?
○ Yes
○ No
○ Maybe

8a.) Why? Please describe:

9). Would you be willing to participate in an interview to share more about your experience with the Respite for Me program?
○ Yes
○ No

9a. Please provide the following information:

Name
Address
Address 2
City
State
Postal code
Email
Telephone Number

Powered by Qualtrics

KII Consent to Participate

Thank you for agreeing to speak with us today. We want to make sure that you understand that your participation in this conversation is voluntary. You can choose not to answer any questions you don't want to. You can end your participation and leave the call at any time. Your participation will not affect any services or benefits you or your care recipient receive.

To make sure that we don't miss anything in our conversation, we would like to make an audio recording of this discussion. We will not share your comments with anyone in a way that you can be personally identified. We will not list your name on the written notes or reports and all information that we collect will be kept in a private and secure way. The information you share with us will be kept confidential and will be combined with the responses from other caregivers who agree to be interviewed. We will use this information to create a report, and once that report is final and the project is complete, we will destroy the underlying recordings and transcripts.

KII Questions

1. How did you hear about the Respite for ME Grants program ?

2. What type of caregiving and respite support did you have **prior to** the Respite for ME Grants program ?

3. What are some experiences with the program that stick out to you?
    a. Probes: What types of services do you receive, e.g., Respite, self-care, chore, assistive technology? Were you able to obtain the services you wanted quickly?
    b. Do you feel like there was enough flexibility in what was allowed to be paid for by the program? Please describe.

4. From our survey, people commonly mentioned that the Respite for ME Grants program provides support that impacts their ability to work, care for family members or themselves, or to do household chores. Is that your experience as well?

    a. Probe if Yes: Please tell us more about that. – *could also probe the specifics of work, caregiving, self-care, chores.*

5. How has the financial support from the Respite for ME Grants program helped alleviate the financial pressures associated with caregiving?
    a. Probe: How has this impacted your daily life and overall well-being?

6. If there was one or two things you could change about the program, what would they be?

7. If there anything else you would like to share about your experience with the Respite for ME Grants program ?

UNIVERSITY OF SOUTHERN MAINE