

# MAINE STATE LEGISLATURE

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January 12, 2022

Senator Ned Claxton, Senate Chair  
Representative Michele Meyer, House Chair  
Joint Standing Committee on Health and Human Services  
100 State House Station  
Augusta, Maine 04333-0100

Dear Senator Claxton and Representative Meyer,

Thank you for your support for LD 1624, Resolve to Create a Stakeholder Group To Identify the Needs of Long-term Care Family Caregivers. In response to this legislation, the Maine Long-Term Care Ombudsman Program, the Department of Health and Human Services, Office of Aging and Disability Services and AARP Maine worked together to convene the stakeholder group to consider and make recommendations for the implementation of a family caregiver needs assessment.

We are pleased to provide you with the report resulting from our work in recent months. The report includes recommendations for an initial plan to address family caregiver needs. We look forward to continued work with stakeholders to ensure that the needs of Maine's approximately 181,000 family care partners across the state are recognized.

We are very appreciative of the funding support for the stakeholder group facilitation provided by the Bingham Program and AARP Maine. We would be pleased to review our report with you at your convenience.

Sincerely,

Brenda Gallant  
Executive Director  
Maine Long-Term Care Ombudsman Program

Karen Mason  
Associate Director  
Aging and Long-Term Services & Supports  
Office of Aging and Disability Services  
Maine Department of Health and Human Services

Noël Bonam  
Maine State Director  
AARP Maine



## Report to the Joint Standing Committee on Health and Human Services

**Submitted by:** Maine Long-Term Care Ombudsman Program;  
Maine Department of Health and Human Services, Office of Aging and Disability Services; and  
AARP - Maine

**Submitted on:** January 7, 2022

### I. Introduction

On June 11, 2021, Governor Mills signed a Resolve to charge the Maine Long-Term Care Ombudsman Program with convening a stakeholder group to consider and make recommendations for the implementation of an assessment system to address the needs of family care partners. The H.P. 1208 - L.D. 1624 Resolve (**Attachment A**), required the establishment of a stakeholder group to identify the needs of long-term care family caregivers (herein called the Stakeholder Group). Members of the Stakeholder Group, and staff from the Maine Long-Term Care Ombudsman Program, Maine's Department of Health and Human Services, Office of Aging and Disability Services (DHHS/OADS), and AARP-Maine contributed to this effort. In addition, AARP - Maine and The Bingham Program in Maine provided funding to engage a facilitator to support this effort.

Family caregivers, herein referred to as family care partners, are integral to an effective system to assure the health and well-being of individuals receiving long-term services and supports. Maine is home to approximately 181,000 unpaid family caregivers. (AARP Valuing the Invaluable, 2019). The needs of family care partners often go unrecognized leaving them without the support they need.

"Being a caregiver for a loved one is profoundly challenging, both physically and emotionally. It is very difficult to find the time or energy to identify resources to alleviate the burden when you are juggling many demands of caregiving. I am very grateful that the Maine Legislature wishes to connect caregivers with resources to lighten the load which will benefit not only the caregiver but also the person who needs that care. I appreciate the opportunity to have served on the stakeholder committee to identify the needs of family caregivers." Jane Conrad, Family Care Partner

## II. RAISE Family Caregivers Act of 2017

The Recognize, Assist, Include, Support, & Engage (RAISE) Family Caregivers Act of 2017 called for the establishment of a Family Caregiving Advisory Council to advise and provide recommendations to the U.S. Department of Health and Human Services on recognizing and supporting family caregivers ([RAISE Family Caregiving Advisory Council's Initial Report to Congress](#)). One of the recommendations presented in this report focuses on caregiver assessments. Recommendation 2.2 reads as follows – “Engage family caregivers through the use of evidence-supported and culturally sensitive family caregiver assessments to determine the willingness, ability, and needs of family caregivers to provide support.” Maine’s efforts to adopt a standardized assessment process to ensure that Maine family care partners are recognized and supported aligns with the Family Caregiver Act of 2017.

## III. Family Care Partner Assessment Tool

Brenda Gallant, Executive Director of the Maine Long-Term Care Ombudsman Program, as an appointed member of the national Family Caregiving Advisory Council, was able to hear about efforts in other states to address the needs of family care partners. Through Family Caregiving Advisory Council meetings, Brenda Gallant learned about a family care partner assessment tool called TCARE®, a national screening, assessment, and tracking system used by some states to address family care partner needs. TCARE® reports positive outcomes ranging from delayed nursing facility placements to reduced caregiver burnout (<https://www.tailoredcare.com/>). As part of a recent federal grant opportunity, DHHS/OADS will be rolling out TCARE® in the five Area Agencies on Aging in spring of 2022.

## IV. Maine’s Stakeholder Group to Identify the Needs of Family Caregivers

The Maine Long-Term Care Ombudsman Program in collaboration with DHHS/OADS and AARP Maine (herein referred to as the ‘Convening Entities’) convened the Stakeholder Group. The Stakeholder Group included family care partners; staff from Area Agencies on Aging, providers, and advocacy organizations; staff from the Convening Entities; Representative Margaret Craven, who sponsored the legislation that established the Stakeholder Group, U.S. Senator Collin’s Office and U.S. Senator King’s Office. The list of members of the Stakeholder Group is attached to this Report (**Attachment B**). The Stakeholder Group met on September 23rd, October 21<sup>st</sup>, November 18<sup>th</sup>, and December 17, 2021.

## V. Stakeholder Group Meetings

### 1) September 23, 2021 - Thirty-four stakeholders attended the first meeting.

The focus of the first meeting was to provide the goals and objectives of the Stakeholder Group, to hear about the State of Washington’s efforts to assess and address the needs of family care partners ([https://leg.wa.gov/JointCommittees/ADJLEC/Documents/2014-05-19/Tailored\\_Caregiver\\_Assess\\_Ref\\_System\\_Impact\\_Report.pdf](https://leg.wa.gov/JointCommittees/ADJLEC/Documents/2014-05-19/Tailored_Caregiver_Assess_Ref_System_Impact_Report.pdf)), to learn about the TCARE® family caregiver assessment system, and to share discussion questions to prepare for the next meeting.

2) **October 21, 2021** - Twenty-three stakeholders attended the second meeting.

The focus of the second meeting was to:

- Highlight the RAISE Report.
- Hear about Maine's Office of Aging and Disability Services Plans for TCARE®.
- Gather feedback from the Stakeholder Group related to the screening and assessment process to assess the needs of family care partners in Maine, and to identify outreach strategies to ensure that family care partners have access to the assessment system and services available to support their ongoing caregiving responsibilities.

The Stakeholders Group broke out into three separate discussion subgroups focused on screening, assessment, and outreach. The following is an overview of the feedback from the Stakeholder Group in each of the three areas.

**A. Screening Subgroup** - Discussion Questions:

- Should Maine adopt a screening tool to determine if the comprehensive TCARE® assessment should be administered?
- If so, can a care partner complete a screening online, or should it be administered by a case manager, service provider, or other community support staff?

Feedback from Stakeholders:

- i. Target who gets an assessment to effectively utilize resources using a screening or algorithm (Maine can decide what triggers a full assessment after the screening).
- ii. Screening makes sense, but we need be sure that we are not duplicating efforts.
- iii. Provide both online, telephone and face-to-face screenings (internet is not available in parts of the state).
- iv. Standardized screening and assessments can help with the training for new staff.
- v. How will screenings be funded?

**B. Assessment Subgroup** - Discussion Questions:

- Once referred for a comprehensive assessment, who conducts this assessment? DHHS/OADS will designate the five Area Agencies on Aging to conduct TCARE® assessments. Should home care agencies, service coordination agencies as well as other agencies also conduct these assessments?
- Who is responsible to ensure that care partner needs are addressed after the TCARE® assessment?

Feedback from Stakeholders:

- i. Not every family care partner is connected with the Area Agencies on Aging.
- ii. The TCARE® assessment is a good opportunity to chip away at agency silos.
- iii. Who makes the referral for the assessment and does the referral source have access to the results and recommendations?

- iv. Who will be responsible to ensure that care partner resources are provided? (this should be a trusted source)
- v. Need to ensure that family care partner needs are met.
- vi. How will the state sustain the provision of TCARE® assessments on an ongoing basis?
- vii. It would be helpful if the stakeholder group had a demonstration of the TCARE® assessment system.

**C. Outreach Subgroup - Discussion Questions:**

- How will family care partners be informed of and have access to the screening tool/assessment system?
- Should hospitals and other health care providers give information about caregiver screening and assessments to family care partners?

**Feedback from Stakeholders:**

- i. Initiate public education campaign including tv ads, brochures that help individuals identify themselves as care partners and where to get more information.
- ii. Develop a central website or a page on [maine.gov](http://maine.gov) for family care partners.
- iii. Develop brochures and be sensitive to limited English proficiency, deaf community, and literacy.
- iv. Engage primary care physician offices and specialists to identify care partners and refer to resources (VA developed a questionnaire for patients to complete in the waiting room to ascertain if they have someone helping them).
- v. Engage health systems in general such as Northern Light Health who has hospitals, nursing homes, home health agencies and physicians as part of their system.
- vi. Engage large employers/private industry, who have a vested interest in having employees at work, to provide information to employees on care partner resources.
- vii. Engage private insurance and Medicare Advantage Plans to provide information to care partners.
- viii. Ensure Maine 2-1-1 has information on where to refer care partners.
- ix. Educate hospital discharge planners, care coordinators, MaineCare Health Homes and Community Care Teams, home health agencies, and personal support agencies to identify and provide information to care partners.
- x. Start with a pilot in one area of the state.

**3) November 18, 2021 - Twelve stakeholders attended the third meeting.**

Greg Link, Director of the Office of Supportive and Caregiver Services with the ACL/ Administration on Aging, attended the third meeting to share his insight into the Family Caregiving Advisory Council's Initial **RAISE Report** sent to Congress. He also discussed the recommendations included in the **RAISE Report** and how these align with the focus of the work of **Maine's Stakeholder Group to Identify the Needs of Family Caregivers.**

Linda Miller, Vice President of Government Programs, TCARE, Inc., also attend the third meeting to provide a demonstration of the online TCARE® system to the Stakeholder Group.

4) **December 17, 2021** – Twenty-seven stakeholders attended the fourth meeting.

The focus of the fourth meeting was to share the proposed implementation plans with the Stakeholder Group and to hear their feedback.

#### **IV. Convening Entity's Recommendations**

Based on feedback from the Stakeholder Group and staff from Convening Entities, the following is a proposed implementation plan that will identify the needs and improve referrals to services for Maine family care partners.

##### **PHASE 1 (early Spring, 2022)**

A. DHHS/OADS will:

- Identify DHHS/OADS staff responsible for coordinating access for the five Area Agencies on Aging (AAAs) to the TCARE® system.
- Develop TCARE® policies, procedures, and protocols.
- Develop TCARE® outreach materials in collaboration with community partners to educate family care partners about the TCARE® system.
- Establish data elements to be collected, analyzed, and presented to internal and external stakeholders as appropriate, for example, number of screenings conducted statewide, number of assessments conducted by AAAs, percent of family care partners assessed that accessed identified resources, services, and programs.

B. Maine's AAAs will:

- As part of the AAA's Aging and Disability Resource Centers (ADRCs), conduct TCARE® screenings to identify family care partners who could benefit from a TCARE® assessment.
- Have trained and certified TCARE® Specialist to receive referrals from community partners and ADRC staff based on screenings to conduct TCARE® assessments.
- Provide access assistance to assessed family care partners to appropriate community services according to TCARE® policies, procedures, and protocols developed by DHHS/OADS.
- Submit monthly reports to DHHS/OADS.

C. Maine's Long-Term Care Ombudsman Program (MLTCOP) will:

- Refer family care partners to the AAAs for screening and assessment as part of its advocacy for individuals searching for long-term services and supports as well as those already accessing long-term services and supports.

D. DHHS/OADS, MLTCOP, and AARP Maine will:

- Explore partnerships with community-based organizations that serve underrepresented and marginalized populations (e.g., people of color, indigenous peoples, people who identify at LGBTQ+, military veterans, etc.) to ensure equitable access to TCARE® screenings and assessments.

## **PHASE 2 (Spring, 2022)**

A. DHHS/OADS, MLTCOP, and AARP Maine will explore:

- Collaborating with the single Assessing Services Agency to, with the consent of the individual, conduct TCARE® screenings to identify family care partners who could benefit from a TCARE® assessment.
- Collaborating with the Service Coordination Agencies, with the consent of the individual, to explore the possibility of conducting TCARE® assessments for family care partners of individuals receiving long-term services and supports and to include family care partners in care planning.
- Partnerships with interested hospitals, home health agencies, and other healthcare partners and provide TCARE® information (developed by DHHS/OADS) to expand the implementation of TCARE® screenings during the care planning process to, with the consent of the individual, identify family care partners who could benefit from a TCARE® assessment.
- Collaborating with hospitals, home health agencies, and other healthcare partners to assure that family care partners are recognized members of the care team and are included in the discharge planning process with the consent of the individual.
- Collaborating with health homes and primary care providers to provide information to family care partners about caregiver resources.
- Partnerships with community-based organizations that serve other family care partner populations (for example, care partners of those with intellectual and developmental disabilities, mental health and substance use disorders, etc.) to expand TCARE® screenings and assessments across the state.

B. DHHS/OADS, MLTCOP, and AARP Maine will:

- Collaborate with TCARE®, Inc. staff to connect with other states using the TCARE® system to hear about lessons learned and best practices (for example, if using a 'no wrong door' approach to conducting TCARE® screenings, how will Maine assure that family care partners are not subject to multiple screenings?).
- Identify gaps in resources needed to support family care partners in Maine and work to address these gaps.



## V. CONCLUSION

We would like to thank the members of the Stakeholder Group for their input and ideas. We are very appreciative of the financial support provided by The Bingham Program and AARP Maine for Stakeholder Group facilitation important in this effort. We were especially fortunate to have family caregiver participation in our meetings. Their firsthand experiences with providing care to loved ones were critical in the development of the plan to begin to address the needs of family care partners across the state. We would like to thank Representative Margret Craven as sponsor of LD 1624. We would also like to acknowledge the input provided by Linda Miller, TCARE® at all of our meetings.

There are approximately 181,000 family caregivers in Maine. (AARP Valuing the Invaluable, 2019). All too often, these caregivers struggle alone without the information and support that can make all the difference in providing care to a loved one. Washington state has demonstrated that addressing family caregiver needs through the implementation of a screening tool along with the TCARE® assessment can significantly improve the quality of life for family care partners resulting in delayed admission to nursing homes creating substantial savings in the Medicaid budget.

The RAISE Family Caregiving Council's first report to Congress has created a roadmap for states to consider in moving forward in developing comprehensive support programs for family caregivers. The Stakeholder Group's plan for implementing the TCARE® assessment system is a first step in building an effective approach to recognizing family partner needs.

STATE OF MAINE

—  
IN THE YEAR OF OUR LORD  
TWO THOUSAND TWENTY-ONE

—  
H.P. 1208 - L.D. 1624

**Resolve, To Create a Stakeholder Group To Identify the Needs of Long-term Care Family Caregivers**

**Emergency preamble.** Whereas, acts and resolves of the Legislature do not become effective until 90 days after adjournment unless enacted as emergencies; and

**Whereas,** family caregivers are critical to the health of individuals receiving long-term care assistance; and

**Whereas,** this resolve requires the long-term care ombudsman program to convene a stakeholder group to consider and make recommendations for the implementation of an assessment measure for the needs of family caregivers in the State; and

**Whereas,** this assessment must be initiated before the 90-day period expires in order that the work may be completed and a report submitted in time for submission to the next legislative session; and

**Whereas,** in the judgment of the Legislature, these facts create an emergency within the meaning of the Constitution of Maine and require the following legislation as immediately necessary for the preservation of the public peace, health and safety; now, therefore, be it

**Sec. 1. Long-term care ombudsman program to establish stakeholder group. Resolved:** That the long-term care ombudsman program, established pursuant to the Maine Revised Statutes, Title 22, section 5106, subsection 11-C and referred to in this resolve as "the long-term care ombudsman," shall establish a stakeholder group to consider and make recommendations for the implementation of an assessment measure for the needs of family caregivers.

**Sec. 2. Stakeholder group membership. Resolved:** That the long-term care ombudsman shall invite the participation of representatives of the Department of Health and Human Services, the area agencies on aging, service coordination agencies for recipients of home care services, Legal Services for the Elderly, Disability Rights Maine, the agency designated by the State to provide statewide assessments as required by the federal Centers for Medicare and Medicaid Services, hospitals, a statewide organization representing home care service providers and a home care service provider, as well as

family caregivers and any other interested parties, in the stakeholder group established in section 1.

**Sec. 3. Duties. Resolved:** That the stakeholder group established in section 1 shall consider and make recommendations for the implementation of an assessment measure of the needs of family caregivers. The stakeholder group shall consider all relevant data including data currently collected by the Department of Health and Human Services or stakeholders relating to the needs of family caregivers and family members of individuals receiving long-term care services at home for referrals for support services and resources, apparent gaps in resources and information regarding family caregiver assessment services and resources provided in other states. The stakeholder group shall also develop a plan to implement improved referrals to services for family caregivers.

**Sec. 4. Report. Resolved:** That the long-term care ombudsman shall submit a report with its findings and recommendations pursuant to section 3, along with any recommended legislation, to the Joint Standing Committee on Health and Human Services no later than January 2, 2022. The committee is authorized to submit legislation to the Second Regular Session of the 130th Legislature related to the report.

**Emergency clause.** In view of the emergency cited in the preamble, this legislation takes effect when approved.

ATTACHMENT B

Stakeholder Group to Identify the Needs of Long-term Care Family Caregivers in Maine

Stakeholders	Organization or representing:	9/23	10/21		11/18	12/17*	Email
Jane Conrad	Family caregivers	√	√		√	√	<a href="mailto:okalee1@aol.com">okalee1@aol.com</a>
Melissa Huston	Family caregivers	√	√				<a href="mailto:melissa.h.huston@gmail.com">melissa.h.huston@gmail.com</a>
Peggy Jean	Family caregivers	√					<a href="mailto:poisadie@aol.com">poisadie@aol.com</a>
Cheryl Chasse	Family caregivers						<a href="mailto:jettawaymiss5@gmail.com">jettawaymiss5@gmail.com</a>
Drew Wyman	Alzheimer's Association						<a href="mailto:dwyman@alz.org">dwyman@alz.org</a>
Amy Angelo	Alzheimer's Association	√	√				<a href="mailto:alangelo@alz.org">alangelo@alz.org</a>
Heather Davis	SeniorsPlus Area Agency on Aging	√					<a href="mailto:hdavis@seniorsplus.org">hdavis@seniorsplus.org</a>
Meredith Anderson	Southern Maine Area Agency on Aging	√	√				<a href="mailto:manderson@smaa.org">manderson@smaa.org</a>
Katlyn Blackstone	Southern Maine Area Agency on Aging	√					<a href="mailto:kblackstone@smaa.org">kblackstone@smaa.org</a>
Ruth White	Aroostook Area Agency on Aging	√					<a href="mailto:Ruth.White@aroostookaging.org">Ruth.White@aroostookaging.org</a>
Tabitha Caso	Eastern Area Agency on Aging	√	√		√	√	<a href="mailto:tcaso@eaaa.org">tcaso@eaaa.org</a>
Katie Carlson	Spectrum Generations Area Agency on Aging	√	√			√	<a href="mailto:kcarlson@spectrumgenerations.org">kcarlson@spectrumgenerations.org</a>
Peter Rice	Disability Rights Maine		√				<a href="mailto:pmrice@drme.org">pmrice@drme.org</a>
Leo Delicata	Maine Legal Services for the Elderly	√	√		√	√	<a href="mailto:ldelicata@mainelse.org">ldelicata@mainelse.org</a>
Betsy Grass	Alpha One	√	√		√		<a href="mailto:bgrass@alphaonenow.org">bgrass@alphaonenow.org</a>
Michelle Way	Alpha One	√	√		√		<a href="mailto:mway@alphaonenow.org">mway@alphaonenow.org</a>
Serena Butterfield	Alpha One	√	√		√	√	<a href="mailto:sbutterfield@alphaonenow.org">sbutterfield@alphaonenow.org</a>
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Laura Moody	Maximus	√			√	√	<a href="mailto:lauralmoody@maximus.com">lauralmoody@maximus.com</a>
Jessica Maurer	Maine Council on Aging	√				√	<a href="mailto:jmaurer@mainecouncilonaging.org">jmaurer@mainecouncilonaging.org</a>
Lisa Harvey-McPherson	Northern Light Health	√	√			√	<a href="mailto:lmcpherson@emhs.org">lmcpherson@emhs.org</a>
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Kandi Sock	Aroostook Band of Micmacs	√					<a href="mailto:ksock@micmac-nsn.gov">ksock@micmac-nsn.gov</a>
Michael Augustine	Penobscot Nation	√					<a href="mailto:Michael.Augustine@penobscotnation.org">Michael.Augustine@penobscotnation.org</a>
Rachel Dyer	DD Council		√				<a href="mailto:rachel.m.dyer@maine.gov">rachel.m.dyer@maine.gov</a>
Simonne Maline	Consumer Council System of Maine	√	√		√		<a href="mailto:smaline@maineccsm.org">smaline@maineccsm.org</a>
Heidi McCaffery	MaineHealth Care at Home	√					<a href="mailto:hmccaffery@mhcah.org">hmccaffery@mhcah.org</a>
Rep. Margaret Craven	Maine Legislature	√	√			√	<a href="mailto:Margaret.Craven@legislature.maine.gov">Margaret.Craven@legislature.maine.gov</a>
Deidre Grant	U.S Senator Collin's Staff	√					<a href="mailto:Deidre_grant@collins.senate.gov">Deidre_grant@collins.senate.gov</a>
Teague Morris	U.S Senator King's Staff					√	<a href="mailto:Teague_Morris@king.senate.gov">Teague_Morris@king.senate.gov</a>
Karen Mason	Office of Aging and Disability Services	√				√	<a href="mailto:Karen.Mason@maine.gov">Karen.Mason@maine.gov</a>
James Moorhead	Office of Aging and Disability Services	√	√		√	√	<a href="mailto:james.moorhead@maine.gov">james.moorhead@maine.gov</a>

ATTACHMENT B

Michelle Cloutier	Office of Aging and Disability Services	√	√			√	<a href="mailto:Michelle.Cloutier@maine.gov">Michelle.Cloutier@maine.gov</a>
Bridget Quinn	AARP	√	√		√	√	<a href="mailto:bquinn@aarp.org">bquinn@aarp.org</a>
Brenda Gallant	Long-Term Care Ombudsman Program	√	√			√	<a href="mailto:bgallant@maineombudsman.org">bgallant@maineombudsman.org</a>
Trish Thorsen	Long-Term Care Ombudsman Program	√	√		√	√	<a href="mailto:tthorsen@maineombudsman.org">tthorsen@maineombudsman.org</a>
Danielle Malcolm	Long-Term Care Ombudsman Program	√	√			√	<a href="mailto:dmalcolm@maineombudsman.org">dmalcolm@maineombudsman.org</a>
Allison Knight	Long-Term Care Ombudsman Program	√	√		√	√	<a href="mailto:aknight@maineombudsman.org">aknight@maineombudsman.org</a>
Linda Miller	TCARE, Inc.	√	√		√	√	<a href="mailto:linda@tcare.ai">linda@tcare.ai</a>
Pat Rivard	Facilitator	√	√		√	√	<a href="mailto:PMRivard@aol.com">PMRivard@aol.com</a>

\*Attended Meeting on 12/17

- Betsy Sawyer-Manter, SeniorsPlus
- Joy Barresi Saucier, Aroostook AAA
- Chris Beaulieu, Aroostook AAA
- Rebecca Kirk, Eastern AAA
- Nate Miller, Spectrum Generations
- Violet Nalley, Spectrum Generations
- Kristin Overton, Spectrum Generations