



RHODE ISLAND STATE PLAN FOR FAMILY CAREGIVERS

JULY 2021 - SEPTEMBER 2023



Family Caregiver Alliance
of Rhode Island



RHODE ISLAND OFFICE OF
Healthy Aging

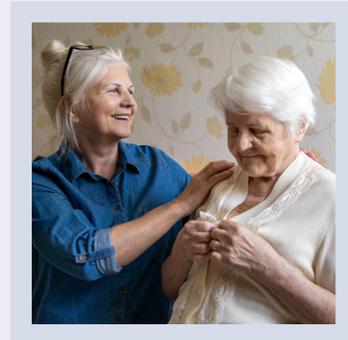


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RHODE ISLAND STATE PLAN FOR FAMILY CAREGIVERS

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“There are only four kinds of people in this world:

- Those who have been caregivers
- Those who currently are caregivers
- Those who will be caregivers
- Those who will need caregivers.”

Rosalynn Carter
Philanthropist and
Former First Lady



At the Rhode Island Office of Healthy Aging (OHA), our mission is to empower people to age strong. Our work is centered in providing information and resources that promote agency and equity, and it's grounded in the belief that people's needs and preferences are diverse and multi-dimensional as they age—and should always inform how we serve.

Rhode Island is growing older. Today, we are among the U.S. states with the highest share of adults age 85 and over, and by 2040, one in four residents will be an older adult. At the same time, there are more than 130,000 care partners in our state, supporting their loved ones in aging with dignity and purpose; this number will only continue to swell. At some point in our lives, most—if not all—of us will find ourselves at one, or both, ends of this care spectrum.

OHA is proud to be a founding member and funder of the Family Caregiver Alliance of Rhode Island—a group dedicated to supporting care partners and their families in our state. We are equally proud to present the inaugural Rhode Island State Plan on Caregiving, which will serve as a valuable tool in our continued work to shape policy and programs that benefit older adults and care partners.

We are building on a strong foundation: one that considers families holistically, as well as the evolving landscape. Rhode Island's respite services are nationally recognized and support caregivers across the lifespan, including an increasing number of grandparents who are raising grandchildren. Despite a global pandemic raging around us, we've continued to deliver high-quality programs and offer virtual workshops to families to help them navigate what is often a challenging—albeit rewarding—caregiver role.

The COVID-19 crisis has disproportionately impacted our elders and placed considerable strain on caregivers. It has also highlighted the deep and historic inequities that plague our state. The data is clear: where you live and your access to resources have a very real effect on your health and quality of life.

We must commit ourselves to creating meaningful opportunities for communities with concentrated disadvantage and to increasing the cultural relevancy of our programs and services.

Thank you to everyone who contributed to Rhode Island's first State Plan on Caregiving. We appreciate your partnership and look forward to all we will do together to support care partners. And most importantly, thank you to the many caregivers across Rhode Island for your selfless acts of love and generosity.

A MESSAGE FROM **Family Caregiver Alliance** of Rhode Island

Welcome to the first Rhode Island State Plan for Family Caregivers. The Family Caregiver Alliance of Rhode Island (FCARI) is proud to work with community partners to improve the access of family caregivers to services across Rhode Island. The following plan will serve as a guide for goals and strategies to strengthen partnership, organizational operations and program offerings for each of Rhode Island's caregivers.

In July of 2017, the Family Caregiver Alliance of Rhode Island became incorporated and obtained 501(c)(3) status as a subsidiary under the United Way of Rhode Island (UWRI), the State's lead partner and operator of the Point. FCARI maintains its independence from UWRI, but utilizes the benefits of non-profit status through UWRI.

With our partners, FCARI has become an advocate for caregiving across the lifespan throughout Rhode Island. Although we have accomplished so much, a large percent of our family caregivers still do not receive the assistance they might need and qualify for within our current framework. FCARI and our community partners see this as an area we can work upon, to improve connection and access to services and resources.

The Family Caregiver Alliance of Rhode Island, in partnership with the Office of Healthy Aging, hopes to bridge this gap with our groundbreaking 2020 RI State Plan for Family Caregivers. Our State Plan aims to expand and implement various programs and partnerships to strengthen FCARI leadership, and ensure that we can secure future funding for programs that will help our caregivers.

Through 2023, FCARI and our partners will continue to ensure our work is responsive to Rhode Islander's by being supportive and present in the community, educating ourselves regarding issues caregivers are grappling with, and most importantly, ensuring equitable access to resources and advocacy for all of our caregivers.

MARYAM ATTARPOUR
PROGRAM MANAGER
FAMILY CAREGIVER ALLIANCE OF RHODE ISLAND

“WE BELIEVE...

- In caregivers and their dedication
- In partnerships and collaborations that further advocate for caregivers and their loved ones
- In increasing the range of services and options to families”

— **Family Caregiver Alliance of Rhode Island Mission Statement**

EXECUTIVE SUMMARY

The Lifespan Respite Care Program was first authorized by Congress in 2006 under Title XXIX of the Public Health Service Act (42 U.S.C 201). Lifespan Respite Care programs are coordinated systems of accessible, community-based respite care services for family caregivers of children and adults of all ages with special needs.

Championed by Rhode Island's own Congressman James Langevin, Rhode Island was one of the first states to receive funding under this Title. Included in the 2006 provisions for funding was the existence in each state of a Caregiver Alliance, serving as a voice for caregivers across the lifespan.

Today's Family Caregiver Alliance of Rhode Island (FCARI) is the result of these earlier efforts. A component of United Way of Rhode Island, FCARI operates as its own entity while benefiting from the extensive umbrella of the United Way, which is also Rhode Island's home to 211 and Point.

This State Plan to Support Family Caregivers is yet another first for Rhode Island. The development of this plan was proposed under the Lifespan Respite Program operated by the State Office of Healthy Aging. It will be the first of its kind in the United States.

This plan is a beginning effort to provide a laser focus on the needs of caregivers caring for Rhode Islanders of any age. This plan will begin in July of 2021 and end in September 2023, coinciding with the State Plan on Aging, the broader document which provides a blueprint for the Office of Healthy Aging.

Included in this plan you will find information about Rhode Island's caregivers, the state's current efforts to support and serve them and goals and objectives to move us forward in this mission.

By 2023 this plan projects:

- An Alliance with a stronger voice for all Rhode Island caregivers
- An Alliance with a more robust website and an enhanced social media presence
- An Alliance with a much-expanded organization included a focus on diversity, equity and inclusion
- An Alliance with a much greater role in supporting the broader State efforts of Caregiver Assessment, Person Centered Options Counseling and No Wrong Door access to long term services and supports.

Special thanks to the many partners and caregivers who provided input to this plan and who will continue to play an important role in achieving these goals.



Many caregivers **do not currently qualify** for respite services through state programs. **Outdated income guidelines** do not reflect the current cost of living. **This needs to change.**

WHO ARE RHODE ISLAND'S CAREGIVERS?

According to the *2020 AARP Caregiving in the US Report*, “the number of Americans providing care has increased in the past five years,”² —and Rhode Island is no exception. More and more Rhode Islanders will find themselves providing care for their loved ones in the coming years, and 24% or more of those individuals will be providing care for one or more persons.²

Women provide 61% of unpaid care in the US, when comparably men in 2020 provide the remaining 39%.² These trends, although studied in RI's aging population and the US caregiver population, may also be used to predict challenges our caregivers are facing, and how we may address them.

It is estimated that 136,000¹⁴ Rhode Islanders care for a family member or friend on a regular basis. The financial and physical toll sustained caregiving takes on the caregiver is well documented.

In spite of these large numbers of Rhode Island caregivers, the number who access and utilize support services is low. The CareBreaks program provides respite breaks to 355¹⁵ families in an average year.

The TDI program for caregivers was utilized by 51,534 during the 2020 calendar year.¹⁶ Of the 51,534 initial TDI applications filed 2020, 16,139 (31.3%) were Temporary Caregiver Insurance Benefits (TCI).⁷

Only a few hundred of Rhode Island's caregivers have taken advantage of the Powerful Tools for Caregivers, a free 6-week course designed to strengthen caregiver skills.

This State Plan for Family Caregivers seeks to advocate for expanded resources to support caregivers. But just as important, will be the efforts to get the word out—to individuals who do not identify as caregivers, those who are unaware of resources, and those who do not know they are eligible for assistance.



“There are an estimated **53 million family caregivers** in the country, and **respite care** continues to be one of their most frequently reported **unmet needs.**”

Congressman James Langevin

WHAT WE DO WELL IN RHODE ISLAND

No matter how successful, all programs and services must grow and adapt to changing circumstances. Rhode Island is fortunate to have a solid foundation of programs and services in place on which to continue to build a more comprehensive network for family caregivers across the Lifespan. While this State Plan for Family Caregivers is not a resource document, we have provided a brief review of current components to the network of support for family caregivers. For a list of programs and contact information for each, please visit fcari.org.

ACCESS — FINDING THE WAY

Getting started as a caregiver sometimes comes as a surprise. You start off by helping a little, then a little more, and then you are it — the primary caregiver. In Rhode Island the following programs and services can help link caregivers to services and supports.

211

In July 2000, the Federal Communications Commission (FCC) reserved the 211-dialing code for community information and referral services. By simply dialing 211, those in need of assistance can be referred, and sometimes connected, to appropriate agencies and community organizations. Dialing 211 helps direct callers to services for, among others, the elderly, the disabled, those who do not speak English, and those with a personal crisis.

POINT | 401-462-4444

Rhode Island's free healthy aging helpdesk at (401) 462-4444. Available — 24 hours a day, 7 days a week, 365 days a year. You will speak with a trained specialist. And your call will be completely confidential.

RIPIN | CALL CENTER 401-270-0101

RIPIN is a nonprofit organization established in 1991 by a group of parents of children with special needs. These parents recognized that together they could provide support through sharing essential information and helping to find the resources they needed for their loved ones. This peer model continues to be at the heart of RIPIN and their expansion statewide.

Today RIPIN employees over 100 folks, most of whom have personal experience caring for a loved one with special health care or educational needs.

The RIPIN Call Center offers free support to any Rhode Islander who needs help accessing healthcare, health insurance, or special education for children with disabilities.

ELDERCARE LOCATOR | 1-800-677-1116

The Eldercare Locator is the first step to finding resources for older adults in any U.S. community. It is a free national service of the Administration for Community Living that provides an instant connection to resources that enable older persons to live independently in their communities and offers support for caregivers. The Eldercare Locator is administered by The National Association of Area Agencies on Aging. This is a good resource for family members caring long distance (in a state other than Rhode Island).

SERVICE — GETTING THE JOB DONE

The tasks involved in caregiving may seem overwhelming. From driving folks to appointments, paying bills and cooking to bathing, toileting and feeding, each caregiver's tasks are as unique as the loved one for whom they care.

Asking for help is not a sign of weakness but an awareness that it is sometimes impossible, and most times unhealthy, to try to do it all yourself. Programs such as the ones listed below can help. Some care recipients will meet criteria that helps them pay for this care.

WHAT WE DO WELL IN RHODE ISLAND

Most others will be private pay — paying for the services based on the provider’s fee schedule. All can help the caregiver do the best possible job.

HOME AND COMMUNITY BASED SERVICES

These programs provide help in the home enabling care recipients to keep living in the community. For some folks who meet eligibility requirements there are programs that help pay for these services. A small number of caregivers may be able to get paid for the care they provide. And finally, for many other folks Home and Community Based Services are private pay.

ADULT DAY HEALTH CENTERS

Adult day health centers offer programming for people with care needs during the day. Services are tailored to the individual and may include therapeutic activities, transportation, meals, and personal care. The programs can help give a break to a round-the-clock caregiver.

CARE RECIPIENT SPECIFIC ASSISTANCE

Many organizations exist to help caregivers who care for someone with a specific diagnosis or disability. For example, the Rhode Island Chapter of the Alzheimer’s Association, the Rhode Island Traumatic Brain Injury Association, and the Autism Association of Rhode Island, to name a few. Some organizations are available to help care recipients who meet certain criteria, like services available for veterans.

For more information on a broad range of Home and Community Based Programs or to apply for assistance contact Point at 401-462-4444.

SUPPORT FOR THE CAREGIVER

Caregiving is an extraordinary gift that often takes a financial, physical and/or emotional toll on the caregiver. The following programs and services, available now to caregivers in Rhode Island, provide assistance and support.

CASE MANAGEMENT

Case management connects a caregiver or care recipient to a trained professional who can help apply for home care services. Case managers can assess a client’s (care recipient) health and human service needs. Case managers assist in planning care, putting care in place, coordinating services, and helping to evaluate options. Case Managers can help a caregiver in doing their very important work.

For some services and programs case management is provided. State funded Home and Community based services usually include case management. Case management may also be provided for some private pay in home services.

RESPITE CARE — CAREBREAKS 401-421-7833 EXT. 212

The CareBreaks program provides assistance in finding and paying for someone to step in and fill the caregiver’s shoes, either on a one time or regular basis. Respite allows the caregiver to take a break, run errands, attend to his/her own personal needs.

RESPITE PROGRAM FOR FAMILIES WITH CHILDREN | (401) 270-0101

Rhode Island offers respite care to parents with special needs children. Eligibility requirements must be met. This program offers a break to the parent/guardian caregiver; time to attend to their own needs or just enjoy dinner and a movie.

WHAT WE DO WELL IN RHODE ISLAND

POWERFUL TOOLS FOR CAREGIVERS 401-432-7217

Powerful Tools is a nationally recognized program that teaches caregivers the skills they need to keep themselves healthy while providing excellent care for their loved ones. The program is offered in six segments and is free to the caregivers who attend.

Other training and education opportunities are offered in Rhode Island for caregivers. Many are specific to the diagnosis of the care recipient. For example the Rhode Island Chapter of the Alzheimer's Association provides a variety of early diagnosis workshops and support groups that provide great benefit to caregivers.

FAMILY MEDICAL LEAVE ACT DLT.RI.GOV

The Family and Medical Leave Act (FMLA) is a labor law requiring employers of a certain size to provide employees unpaid time off for serious family health issues or situations. Qualified reasons may include adoption, pregnancy, foster care placement, family or personal illness, or military leave.

FMLA is designed to help employees balance their work and family responsibilities by allowing them to take reasonable unpaid leave.

TCI TEMPORARY CAREGIVER INSURANCE RIPAIDLEAVE.NET

TCI is a benefit available to Rhode Island caregivers who are employed. This program offers up to four weeks of partial wage replacement benefits to workers who need time off from work for:

- Care of a seriously ill child, spouse, domestic partner, parent, parent-in-law or grandparent
- Bonding with a newborn child, adopted child or foster child.



The **Guide for Caregivers** and **Point** are excellent starting points for finding resources to help with caregiving.

To access the guide, visit eohhs.ri.gov/consumer/elders and click on the **Caregiver Guide** under resources.

Point, Rhode Island's free healthy aging helpdesk, offers confidential and multilingual assistance 24 hours a day, 7 days a week, 365 days a year.
(401) 462-4444.

WORK THAT REMAINS TO BE DONE

The work of the Family Caregiver Alliance of Rhode Island (FCARI) is guided by the mission to provide support for all Rhode Island caregivers and those for whom they care, through partnerships, advocacy and inclusion.

GOAL 1

TO PROVIDE A VOICE FOR ALL RHODE ISLAND CAREGIVERS

Objective 1.1

Establish an online enrollment process (“Join the Family Alliance”) for Rhode Island caregivers providing a vehicle for sharing of information, advocacy alerts and calls to action.

Action Steps:

- In July 2021, begin the process of modifying the FCARI website to include a free “Join the Family Alliance” feature for caregivers, offering regular information updates.
- Beginning September 2021, offer “Join the Family Alliance” to caregivers across the lifespan. Work with partner agencies including but not limited to CareBreaks, RIPIN, NAMI, Alzheimer’s Association, attendees at past conferences and forums, and caregivers known to State supported programs.
- Establish procedures to continuously update this enrollment as well as provide regular information to enrollees.

Objective 1.2

Establish a process for monitoring state and federal legislation, policy and procedures that impact caregivers and those for whom they care.

Action Steps

- Establish a standing Advocacy subcommittee of The FCARI Advisory Committee for the purpose of identifying legislation/policy/procedures affecting caregivers and those for whom they care.

- Recruit participation from congressional offices staff, staff at OHA, OHHS, DOH, BHDDH, AARP, The Governor’s Commission on Disabilities and other agencies working with caregivers across the lifespan.
- Assign FCARI staff/volunteers to provide advocacy alerts to caregivers as well as the aging network and partner agencies.

Objective 1.3

Speak out on legislation/policy/procedures affecting caregivers and those for whom they care.

Action Steps

- Assign staff to prepare and deliver testimony on legislation, obtaining input from the Advocacy subcommittee.
- Identify caregivers to testify regarding legislation/policy/procedures relating to caregiving.
- Assign staff and caregiver volunteers to serve on advisory committees/task forces to provide an informed voice for caregivers.

GOAL 1 Performance Measures

1. By December 2021, enroll members of the Advocacy subcommittee and establish subject areas for monitoring.
2. By April 2022, provide regular advocacy updates to the full Advisory committee, partner agencies and the Aging Network.
3. By September 2023, enroll more than 500 caregivers in “Join the Family Alliance.”

WORK THAT REMAINS TO BE DONE

GOAL 2

PROVIDE A ROBUST WEBSITE AND SOCIAL MEDIA PRESENCE FOR THE FAMILY CAREGIVER ALLIANCE OF RHODE ISLAND

Objective 2.1

Expand the information and resources provided on the FCARI website

Action Steps

- Collaborate with the Office of Healthy Aging to identify resources for expansion of the FCARI website.
- Utilize expertise of the Advisory Committee, partner agencies and caregivers to identify content and format for website.
- Collaborate with OHHS to include access to the updated “Guide for Caregivers” through the FCARI website.
- Establish a “Glossary of Terms for Caregivers” component to the website to provide easy access to information for caregivers.
- Establish a “How Rhode Island Law Supports Caregivers” component to the website to provide a succinct summary of these several Rhode Island Laws (see Appendix)

Objective 2.2

Increase social media presence and expand collaboration with partners

Action Steps

- Collaborate with United Way social media staff and Office of Healthy Aging staff to include posts for Facebook, Twitter and other social media sites regarding FCARI.

GOAL 2 Performance Measures

1. By September 2021, identify funding for website expansion

2. By January 2022 establish protocols for regular social media use, approved by both United Way of Rhode Island and the State Office of Healthy Aging.
3. Establish “Glossary of Terms for Caregivers” component of the website by January 2022, with protocols for updates.
4. Establish “How Rhode Island Law Supports Caregivers” component of the website by April 2022, with protocols for updates.
5. Launch expanded website by September 2022

GOAL 3

ENSURE DIVERSITY, EQUITY AND INCLUSION FOR RHODE ISLAND CAREGIVERS AND THOSE FOR WHOM THEY CARE

Objective 3.1

Collaborate with leaders of ethnic and culturally diverse populations in Rhode Island to identify caregivers and potential Advisory Committee members

Action Steps

- Continue the work of identifying leaders in Rhode Island’s ethnic and culturally diverse communities
- Work with partners to establish a FCARI Advisory Committee Subcommittee on Diversity
- Recruit members to inform the work of FCARI, including website expansion and outreach for enrollment of members.

Objective 3.2

Support the Office of Healthy Aging and the State of Rhode Island’s broader efforts to ensure that resources and supports for caregivers are equitably distributed.

WORK THAT REMAINS TO BE DONE

Action Steps

- Assist in the outreach efforts to reach ethnically and culturally diverse populations for enrollment in Powerful Tools for Caregivers
- Assist in outreach efforts to publicize the CareBreaks Program to ethnically and culturally diverse populations.

Objective 3.3

Ensure that caregivers of all cultural and ethnic communities are included in the operations, programs and services designed to provide them with assistance and support.

Action Steps

- Expand the number of caregivers on the FCARI Advisory Committee.
- Review annually the composition of the Advisory Committee and the various subcommittees of FCARI to ensure that input from caregivers is obtained at all levels.
- Continue and expand annual events such as the Caregiver Conference to involve caregivers and obtain input and feedback.

Goal 3 Performance Measures

1. By September 2021, review the membership of the Advisory Committee to ensure that at least 10% of members represent ethnic/culturally diverse communities. Identify strategies to reach 10%, if needed.
2. By December 2021, establish a Subcommittee on Diversity to recruit at least 8 community leaders from ethnic and culturally diverse communities.
3. By September 2022, assist and support at least 4 outreach efforts for Powerful Tools for Caregivers and the CareBreaks Program targeted to diverse communities.

4. By December 2022, increase the caregiver representation on the Advisory Committee and subcommittees by 15%.

GOAL 4

ENSURE THAT THE CAREGIVERS OF RHODE ISLANDERS SEEKING LONG TERM SERVICES AND SUPPORTS ARE IDENTIFIED AND PROVIDED WITH INFORMATION AND ASSISTANCE.

Objective 4.1

Support the Office of Healthy Aging and the Office of Health and Human Services in implementing RIGL 40-8.10-4, as amended in 2019.

Action Steps

- Collaborate with OHA care management agencies and staff of DHS to determine current procedures to implement RGL 40-8.10-4, as amended.
- Collaborate with OHA and DHS in providing information to identified caregivers regarding FCARI.
- Assist in distributing the DHS Caregiver Assessment to non-Medicaid providers of Long-Term Services and Supports as an educational tool for determining the needs of caregivers.

Objective 4.2

Support the Office of Healthy Aging and the DHS in providing outreach to caregivers.

Action Steps

- Collaborate with the Aging Network and partner agencies during open enrollment to identify caregivers.
- Develop a flyer for open enrollment targeting caregivers and available resources.
- Collaborate with CareBreaks, Powerful Tools for Caregivers, RIPIN Hospital

WORK THAT REMAINS TO BE DONE

Transition Program, Alzheimer's Association and partner agencies providing resources for caregivers across the Lifespan.

Objective 4.3

Support the broader State of Rhode Island initiatives to implement No Wrong Door and Person-Centered Options Counseling.

Action Steps

- Utilize the Family Caregiver Alliance membership to promote the goals of the No Wrong Door framework — raising visibility of service options, empowering caregivers and care recipients to make informed decisions, and assisting in access to advice and counseling.
- Utilize the Family Caregiver Alliance membership to educate caregivers and care recipients on the availability of Person-Centered Options Counseling
- Provide training for FCARI staff and Advisory Committee and subcommittees on the State initiatives of No Wrong Door and Person-Centered Options Counseling.

Goal 4 Performance Measures

1. By September, 2021, meet with OHA and OHHS to determine procedures currently in place to implement RIGL 40-8.10-4, as amended in 2019.
2. By September 2021, develop materials for Open Enrollment that target caregivers and focus on resources available.
3. By April 2022, evaluate Open Enrollment Outreach efforts.
4. By April 2022 offer recommendations regarding the caregiver assessment process required by RIGL 40-8.10-4 as amended to OHA and DHS including recommendations for follow up with identified caregivers.

5. By October 2022 identify non-Medicaid providers of Long-Term Services and Supports and share Caregiver Assessment and information on caregiver resources.
6. Update open enrollment materials, annually.

GOAL 5

ADVANCE OPPORTUNITIES FOR DIGITAL ACCESS TO SERVICES AND SUPPORTS FOR RHODE ISLAND CAREGIVERS

Objective 5.1

Collaborate with Office of Healthy Aging digiAge Caregiver Partners in expansion of digital access for caregivers

Action Steps

- Work with OHA to develop a chart summarizing objectives of the 10 grants
- Assist in outreach to caregivers
- Partner with the Village Commons to help publicize their Support Group Circles

Objective 5.2

Identify caregivers in need of assistance to close the gap in digital access

Action Steps

- Refer to State partners identified housing units and neighborhood areas that lack digital connection.
- Identify resources for individuals unable to afford iPads, notebooks, computers, phones or other communication devices.
- Refer caregivers in need of devices for virtual caregiver support to Villages Common.

WORK THAT REMAINS TO BE DONE

Goal 5 Performance Measures

1. By July 2021 identify the various resources available to caregivers through OHA digiAge grants.
2. By July 2021 and ongoing, post schedule for Villages Common Caregiver Support Circles on the Caregiver Alliance website.
3. Track input from caregivers and Advisory Committee members regarding geographic areas or housing situations that do not provide adequate digital access. Provide information to State Partner agencies.
4. Refer caregivers in need of assistance in obtaining communication devices to available resources.

ADDITIONAL RESOURCES MAY BE FOUND ON THE FOLLOWING PAGES

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THANK YOU TO OUR PARTNERS

To our partners, collaborators, and caregivers, who helped us see where we can build and improve upon. Our work would truly not be possible without you.

THIS DOCUMENT WAS CREATED BY



United Way of Rhode Island

IN PARTNERSHIP WITH



WITH CONTENT CONTRIBUTIONS FROM



KATHLEEN M. MCKEON
CONSULTANT

CAREGIVING: AN OVERVIEW

Who Is A Caregiver?

“Caregivers provide regular care or assistance to a friend or family member with a health problem or disability.”¹ This may also include individuals who require care due to a mental health diagnosis. A family caregiver is often times unpaid, and provides the majority of care for their loved-one at home.

Different Types Of Family Caregivers

Whether you’re taking care of an aging parent, a disabled spouse, or looking after a child with a physical or mental illness, providing care for a family member in need is an act of kindness, love, and loyalty. Caregiving may look like:

- Caring for aging parents or loved-ones
- Caring for children with a physical or mental health disability
- Caring for adults with a physical or mental health disability
- **Sandwich Caregivers:** caring for both children and adults simultaneously
- **Kinship Caregivers:** caring full-time for children within the extended family/friend network, who cannot live safely at home

Caregiver Statistics

Let’s refresh our memory with some overall data about caregiving in the US and Rhode Island.

53 MILLION
UNPAID CAREGIVERS IN THE US²

159,477
UNPAID CAREGIVERS IN RHODE ISLAND³

22%
UNPAID CAREGIVERS IN RHODE ISLAND’S
ADULT POPULATION⁴



“...today, more than **1 in 5** Americans are caregivers”

The National Alliance
for Caregiving⁵

Caregiver Strain

WHAT IS IT?

“Caregiver strain and burden encompasses the difficulties assuming and functioning in the caregiver role as well as associated alterations in the caregiver’s emotional and physical health that can occur when care demands exceed resources.”⁶

HOW DOES IT AFFECT FAMILY CAREGIVERS?

“Nearly one in five caregivers report high physical and emotional strain as a result of their caregiving duties.”⁷

Economic Impacts: Caregiver’s Finances

“About half of caregivers have experienced at least one financial impact as a result of caregiving (45%), with 34% who have experienced two or more financial impacts”⁸

28%
STOPPED
SAVING

23%
TOOK ON
MORE DEBT

34%
HAD 2 OR
MORE IMPACTS

Economic Impacts: The US Economy

61%
CAREGIVERS ARE ALSO EMPLOYED
WHILE PROVIDING UNPAID CARE⁹

\$470 BILLION
THE ESTIMATED ECONOMIC VALUE
OF FAMILY CAREGIVING¹⁰

60%
REPORTED THEIR WORK BEING IMPACTED
AS A RESULT OF CAREGIVING⁹

\$7-12,000
AVERAGE ANNUAL OUT OF POCKET COSTS THAT
CAREGIVERS SPEND TO PROVIDE UNPAID CARE¹¹



Although family caregiving adds on **stress and financial uncertainty** for many families, many caregivers express the **joy and reward** they feel while taking care of their loved-one. So, how can we help relieve some of that stress?

CAREGIVER LAWS OF INTEREST

Over the past decade the RI legislature has been responsive to advocates working to improve and expand supports for family caregivers. Below is a list of these important laws. It would be prudent to review these laws to determine how they are being implemented, if adequate resources are available to put them into practice, and the need for any changes or refinements to the law. It would also be important to review legislation that has been submitted in the state legislature and not passed as well as laws and policies in other states to determine their relevancy for supporting Rhode Island family caregivers.

RHODE ISLAND LAWS

2013

The Temporary Caregiver Insurance Law (RIGL28-41)

Provides for up to four weeks of partially paid leave to care for a newborn, newly adopted or fostered child, or to care for a seriously ill spouse, domestic parent, grandparent, grandparent-in-law. The law provides job protection. It is only available to workers who pay into the Temporary Disability program which excludes state employees and the self-employed. More information is available from Rhode Island Department of Labor and Training.

Family Caregiver Assessment Act (RIGL 40-8.10-4)

Requires caregiver assessments used to develop caregiver plan to provide appropriate plan for caregiver information, education and training, referral, and support services. Information about available respite programs, caregiver training, and education programs, support groups, and community support services shall be included as part of the caregiver support plan.

Passed as PL2013-457; amended in 2019 to require annual reports on a number of assessments done, referrals made, and service gaps found.

2015

The CARE (Caregiver Advise, Record, Enable) Act (RIGL 23-17.27)

Helps family caregivers when their loved ones go into the hospital and as they transition home. The CARE Act requires hospitals in Rhode Island to:

- Record your name on the medical record of your loved one;
- Inform you when your loved one is to be discharged to another facility or back home; and,
- Give you live or recorded demonstration of the medical tasks you will need to perform at home such as medication management, injections and wound care.

Note: This link provides excellent information on resources and videos about specific care tasks. <https://www.aarp.org/content/dam/aarp/ppi/2019/03/the-care-act-implementation-progress-and-promise.pdf>

2017

Healthy and Safe Families and Workplaces Act. (RIGL 28-57) Paid Sick Leave

Requires employers with eighteen (18) or more employees to provide 24 hours of paid sick days in 2018, 32 hours paid sick days in 2019 and 49 hours paid sick days thereafter. It allows the sick leave to be taken to care for family members. More information available at Rhode Island Department of Labor and Training.

CAREGIVER LAWS OF INTEREST

2018

Web-based Caregiver Support Center at Office of Healthy Aging (RIGL 42-66-4(b)(18))

Requires the Office of Healthy Aging (formerly Elderly Affairs) to provide a web-based caregiver support information center and further defined the duties of the Office with regard to elder caregiver respite services to include home health/homemaker care, adult day service, assisted living and nursing home care.

The Independent Provider Law.

Enables the creation of a public registry of independent personal aides, giving seniors and individuals living with disabilities another choice when accessing long-term care options. Allows family members to become independent care providers.

Aging and Disability Resource Center (known as the Point/211) was established into law as Article 13 of the state budget bill (PL-2018-47)

Call Point at 401-462-4444 or call 211, or, visit the Office of Healthy Aging/Point website.

2019

Family Caregiver Support Association and Family-caregiver Resource Network Established. (RIGL 42-66-4(b)(19))

Family Caregiver Alliance of Rhode Island was created.

The Rhode Island Program to Address Alzheimer's Disease (RIGL 23-1.7)

Creates Advisory Council on Alzheimer's Disease to compile data on persons with Alzheimer's Disease, available resources, make recommendations on policy, calls on Director to establish assessment protocol, requires professional training on caring for persons

with cognitive impairments, health facilities to have operational plans for recognizing and managing persons with ADRD. Requires annual updating of the state Alzheimer's State Plan. For information, go to health.ri.gov/programs/detail.php?pgm_id=156674.

LEGISLATION INTRODUCED IN RHODE ISLAND

2021

Temporary Caregiver Insurance (TCI) Expansion

All bills expand weeks ranging from 8 to 12 weeks. Some add more types of employees and care recipients)

436 by Sen. Goldin

688 by Sen. Lawson

5789 by Rep. Cassar

6090 by Rep. Kazarian

Rhode Island TCI law which was third such law in nation provides for four weeks of paid leave. Other states have adopted laws with 12 weeks and is now the average as well as expanding persons eligible to take TCI.

2018

Caregiver Assistance and Relief for Elderly (CARE)

Provides for up to \$70/day for support services costs for qualified caregivers allowing families to work/pursue individual needs.

7043 by Marshall

This was based on Hawaii's Kupuna Caregivers Act, a pilot program launched in 2018. Up to \$350/week is provided for support services for persons age 60+. The caregiver must be employed at least 30 hours/week.

CAREGIVER LAWS OF INTEREST

2021

Livable Home Modification Grant Program. Provides grants to eligible homeowners and renters to retrofit residences to nationally recognized accessibility standards

158 by Sen. Felag
5796 by Rep. McNamara

For past two years, funds have been included in state budget (Department of Human Services) to provide these grants. Bill codifies the grants.

Health Insurance Coverage for Accessible Residence Modifications

5072 by McNamara

Would require health insurance plans to provide coverage for accessible residence modifications determined to be medically necessary by physician to prevent placement in long term care facility.

Expansion of Office of Healthy Aging At Home Cost Share Program – eligibility from 200% to 250% of FPL and persons under 65 with ADRD

162 by Felag

5115 by Solomon
Estimated to allow 400 more persons to participate in program and receiving home care and/or adult day services and case management thus delaying or avoiding facility placement.

Tiny Homes allowed as Accessory Dwelling Units.

5632 by Ackerman

Allows tiny homes to be built on family property. May help older adults with care needs live close to family members to help with care.

EXAMPLES OF LAWS AND LEGISLATION FROM OTHER STATES

Hawaii Kupuna Caregiver Law

A pilot program launched in 2018. Up to \$350/week is provided for support services for persons age 60+. The caregiver must be employed at least 30 hrs./week.

NJ Wounded Warrior Caregivers Relief Act

Passed in 2017. Allows for a maximum state income tax credit of \$675 to family caregivers who are assisting a veteran disabled in any armed conflict after September 11, 2001.

Missouri Shared Care Tax Credit

A shared care member registered with the Division of Senior and Disability Services, Missouri Department of Health and Senior Services, may be eligible for a non-refundable tax credit equal to his or her Missouri tax liability or \$500, whichever is less, to offset the cost of caring for an elderly person.

To be eligible for the shared care tax credit, the caregiver must care for an elderly person, age 60 or older, who: is physically or mentally incapable of living alone and requires assistance with activities of daily living to the extent that without care and oversight at home would require placement in a facility (<https://dor.mo.gov/taxcredit/sct.php>)

Wisconsin Governor Evers Family Caregiver Tax Credit Proposal

A \$500 income tax credit to help cover family caregiver expenses. Proposed as part of Governor Evers' 2021 budget.

California Family Caregiver Tax Credit AB-251 by Patterson

Provides for a tax credit up to 50% of amount paid or incurred for eligible expenses related to the care of an eligible family member not to exceed \$5,000. Failed to pass.

CAREGIVER LAWS OF INTEREST

FEDERAL LEGISLATION

2021

Credit for Caregiving Act S. 1670, H.R.3321

Bipartisan bill would provide up to \$5,000 in federal tax credit for eligible working family caregivers for qualified expenses above \$2,000 incurred which would help defray the nearly \$7,000 out-of-pocket costs spent by many caregivers.



“Kindness can transform someone’s dark moment with a blaze of light. You’ll never know how much your caring matters. Make a difference for another today.”

Amy Leigh Mercree
Author

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Family Caregiver Alliance
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