



# THE UTAH **FAMILY CAREGIVER** REPORT 2022

A document that highlights the needs of Utah caregivers and provides a roadmap toward a “state plan” that coordinates relevant policies, programs, and community awareness activities

## Caregiver

*noun*

A relative, partner, friend, or neighbor who provides care and support to individuals, including (but not limited to) those who are aging, chronically ill, or who have physical, intellectual, or developmental disabilities and related conditions.

They may live with, or separately from, the person receiving care. They may be the primary or sole care provider, or they may be a secondary caregiver who shares care responsibilities with others.

Caregivers assess medical and social needs, prepare care plans, assist with activities of daily living, perform medically necessary services, and/or provide companionship and assistance with meals, transportation, housekeeping, legal and financial planning

*Also known as:* **Family Caregiver, Care Partner, Informal Caregiver**

## This work is shaped by the following guiding principles:

### Collaboration

to identify shared priorities among stakeholders across the state

### Diversity & inclusion

to ensure the voices and needs of all types of caregivers and stakeholders are represented

### Coordination & non-redundancy

to share resources and to minimize redundancies (or siloed approaches) in the delivery of service and supports across the state

### Evidence-informed decision making

including systematic collection and analysis of data, to inform and guide policy and strategy decisions

The Utah Family Caregiver Report was created by a Special Committee on Family Caregiving (SCFC), under the powers of the Utah Commission on Aging (Utah Code Title 63M, Chapter 11) and convened with administrative and financial support from the Family Caregiving Collaborative at the University of Utah.

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## Executive Summary

In Utah, like in other states, family caregivers are the backbone of the long-term services and supports infrastructure. They provide direct care and services to family members and friends in homes and communities throughout the state.

Caregiving often extends for many years, and is commonly juggled with paid employment and other family care obligations. While providing care to family and friends is meaningful and fulfilling for many Utahns, it is not uncommon for caregivers to experience social, financial, emotional, and physical health consequences, as a result of the demanding caregiving role.

The services and supports provided by Utah caregivers are largely unpaid, valued at \$5 billion annually. Caregivers further reduce public and out-of-pocket healthcare expenditures by delaying institutionalization, not relying exclusively on at-home health care services, and lowering emergency department use among the persons being cared for. As a result, family caregivers play a role in alleviating the challenges associated with workforce shortages and turnover among direct-care staff of the formal long-term services and supports sector.

Caregivers are vital to our state, deserving of a coordinated statewide policy response that prioritizes and recognizes their invaluable contributions to the health and financial well-being of our state.

The *Utah Family Caregiver Report* provides a blueprint with specific recommendations and measurable outcomes that correspond to the five strategies outlined in the Recognize, Assist,

Include, Support, & Engage (RAISE) National Family Caregivers Act of 2018, while leveraging the unique strengths and opportunities of our state. The *Utah Family Caregiver Report* recommends a set of guiding priorities and specific activities that, if implemented, would help to ensure Utah caregivers, regardless of age, relationship, or condition/illness they are providing care for, will

1. Recognize the important role that they provide to the health and well-being of Utah,
2. Have access to high-quality, culturally relevant resources and supports,
3. Are seen as important partners in health and long-term care decisions,
4. Experience financial and workplace security, and
5. Are supported by evidence-informed research and best practices.

This report has been developed over the last two years by a Special Committee on Family Caregiving (SCFC), with input from a broad range of stakeholders. We are now seeking legislative support to implement the recommendations outlined on page **14**, which include appointment of a Director to manage and track the goals of a “State Plan” focused on family caregivers, and the creation of a Utah Family Caregiver Council which will implement the plan through the collaborative efforts of public and private organizations, research entities, healthcare systems, and family caregivers.

## Family Caregiving in Utah

In 2020 436,000 Utahns were family caregivers, representing approximately **1 in 4 adult** women and **1 in 6** adult men. Among Utahns aged 55–64, nearly 1 in 3 (29.6%) are caregivers.

These prevalence estimates do not account for the future or former caregiving roles assumed by families and friends, or the increasing trend of young persons to provide care within families. Prevalence may be further underestimated, as many persons do not identify as caregivers. They are “just doing what families do.”

Utah caregivers are most often the spouses, parents, and adult children of those requiring assistance. Other relatives (siblings, cousins, grandparents) and non-familial relationships (friends, neighbors) also serve as caregivers.

Utah caregivers provide care for persons with a wide variety of health problems. Fifteen percent care for an adult over the age of 65, with about 1 in 10 caring for someone with Alzheimer’s Disease or related dementia. Over 7% care for someone with developmental disabilities, 5% to someone with a mental illness, and approximately 24,000 Utah children have a grandparent as a primary caregiver (most often because of drug-use or illness of the parent).

About 35,000 Utah caregivers reported providing more than 40 hours of caregiving per week and have been doing so for more than 60 months. Caregivers assist with grocery shopping, meal preparation, arranging for and accompanying the individual to medical appointments, assisting with eating, bathing and dressing, managing household finances, and advocating for benefits. Caregivers are increasingly responsible for activities previously performed by medical professionals, including managing medications, giving injections, and operating medical equipment.

Given the long hours and challenging demands, caregivers commonly experience a **decline in their financial, physical, social, and emotional health**. Financial consequences include lost wages, reduced social security and retirement benefits, and out-of-pocket care expenses. Caregivers often put their own needs below those of the person they are caring for and readily admit that they have put off taking care of their own health or well-being. Feelings of isolation, stress, burden, and lack of appreciation are also common among caregivers.

“There are only four kinds of people in the world: those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregivers.”

-May 26, 2011, Rosalyn Carter



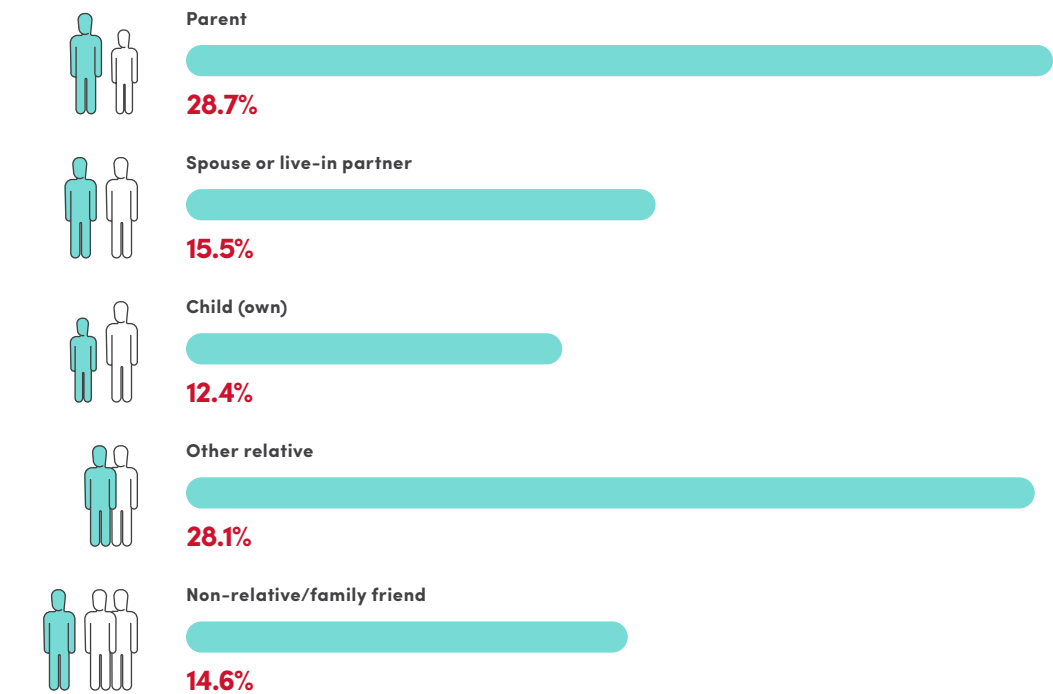
The **economic value** of the work provided by family caregivers is undeniable – in Utah, it is estimated to be about **\$5.1 billion annually and increasing**. Furthermore, their care and support enable care recipients to remain in their homes, avoiding costly nursing home and assisted living care. These significant cost-savings accrue to both families and the state Medicaid budget.

As Utah’s population grows and ages, the need for family caregivers grows. **Family caregivers can be a part of the solution of the growing healthcare crisis**. Supporting caregivers can lower healthcare costs, by directly helping keep the care-recipient healthier, safer and at home, but also by preventing the secondary effects associated with being a caregiver (e.g., mental health crises, injuries related to poor body mechanics or lack of adaptive equipment, lack of self-care).

Family caregivers should be recognized as vital members of the healthcare and long-term services and support teams for our aging, chronically ill, and disabled community members.

Finding ways to support family caregivers must be prioritized as an important public health and public policy issue for Utah.

Figure 1: Who are Utah family caregivers caring for?



Note: Data come from the Utah Behavioral Risk Factor Surveillance Survey. See Appendix C.

## Policies and Programs to Support Family Caregivers

In 2016, the National Academies of Science, Engineering, and Medicine released a report about the needs of individuals providing care to family members, entitled *Families Caring for an Aging America*. The report provides an overview of the prevalence and nature of family caregiving, as well as its impact on caregivers’ health, economic security, and overall well-being. It concluded with a recommendation to develop a national strategy to effectively engage and support caregivers.

### National Caregiving Strategy

In 2018, the United States Congress passed and enacted into law the *Recognize, Assist, Include, Support, & Engage (RAISE) Family Caregiving Act* (public law No. 115-119). This law established a national policy effort related to family caregiving in the U.S. The RAISE Family Caregiving Advisory Council partnered with the Advisory Council to Support Grandparents Raising Grandchildren; each released their own report to Congress, and together, their recommendations have laid the groundwork for the development of a cohesive National Family Caregiving Strategy.

In September 2021, the RAISE Family Caregiving Advisory Council released its initial report to Congress. This report outlined the challenges faced by family caregivers, federal programs currently available to support them, and 26 specific recommendations related to five key strategies, as shown in Figure 2.

The 26 recommendations included, for example, increasing public awareness and recognition of the needs, issues, and challenges of family caregivers (Strategy #1), training of healthcare and social service professionals to maximize caregiver engagement and participation in the formal care team (Strategy #2), increasing availability of high-quality, culturally-relevant services and training to support family caregivers, including volunteer and technology-delivered interventions (Strategy #3), advancing employee-centered workplace policies and practices to support work/life balance (Strategy #4), and establishing a national data infrastructure and standardized data to track caregiver needs (Strategy #5).

Figure 2: 5 Key Strategies  
RAISE National Family Caregiving Report



Predating the RAISE Council report, there were already ongoing national level activities that emphasize the importance of recognizing, valuing, and supporting the work of family caregivers. For example:

- National Family Caregiver Support Program, established in 2000
- Department of Veteran Affairs Caregiver Support Programs, implemented in 2012
- Amendment to the Public Health Service Act (the BOLD Act), 2018

**State Initiatives**

The National Alliance for Caregiving released a report called *Momentum to Movement: Developing a Unified Strategy to Support Family Caregivers Across the Nation*. This report encourages every state to develop state-level strategies to support family caregivers.

As of 2022, 13 states have already created and enacted a “state plan” or created a task force to guide their policy activities and priorities to effectively support family caregivers in their state.



*Note: See Appendix A for more details.*

Examples of Other States’ Actions:

- Increased legislative appropriations, such as increased funding for respite and caregiver support programs
- Caregiver advisory boards to inform policy
- Collection of caregiver stories and testimonials
- Inventory of caregiver services and supports
- Direct compensation of family caregivers, through expansion of tax credits or home-and-community based waivers (HCBS)
- Clarification of guardianship and power-of-attorney regulations to reduce elder abuse and financial fraud
- Designation of caregivers in medical records
- Enhanced hospital discharge planning with caregivers
- Data driven needs assessment and identification of unmet needs among caregivers
- Expansion of Family & Medical Leave Act (FMLA) to be more inclusive of caregiving relationships (familial and non-familial) and to cover those working in businesses with fewer than 50 employees;
- Paid leave for employees who have caregiver responsibilities

*Note: See Appendix A for more details.*

**Utah Actions**

Much work is already underway in Utah – by researchers, healthcare systems, and businesses – to support family caregivers in Utah. For example,

- **Intermountain Health Care** has multiple studies on family caregiving underway.
- The **VA Salt Lake City** is one of five national funded locations for the *Elizabeth Dole Center of Excellence in Veteran and Caregiver Research* and has an established and ongoing research agenda.
- The **University of Utah** created the *Family Caregiving Collaborative* to support an extensive research portfolio that is funded both internally and by National Institutes of Health grants.
- The **Disability Law Center** works with Legally Authorized Representatives for adults with disabilities and helps navigate difficult scenarios and access resources.
- **Hospice and Home Care Association of Utah** has established a new *Family Caregiver Division*.

- **University of Utah Health Plans** provides support to family caregivers through their care management program.
- Several **prominent businesses** provide significant financial supports for caregiving and more are interested in doing so.

In recent years, the Utah Legislature has led with policies that directly or indirectly support family caregivers. For example,

- **Patient Designated Caregiver Rule** (R432-100-12, 2016) requires hospitals to record the name of the patient’s designated family caregiver upon admission and keep that caregiver informed of their loved one’s discharge plans: caregivers have the right to be trained on what is needed in order to maintain care at home.
- **Telehealth Parity Amendments** (HB 313, 2020) expanded insurance for telehealth and telehealth services to include facilitation of self-managed care and caregiver support.

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# The economic value of caregiving in Utah was **\$5.1 billion** in **2020**.

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*Note: Refer to Appendix C for more information.*

**This is the amount of money that would be required today if Utah had to replace the (mostly) unpaid labor done by family caregivers with formal long term services and support. This amount is expected to exceed \$6.5 billion by 2030.**

- **Delegation of Health Care Services Amendments** (HB 274, 2020) empowered a “responsible caregiver” (i.e., spouse, adult child, parent, foster parent, or legal guardian who is primarily responsible for providing nursing care to the patient), to be able to delegate to an unlicensed direct care worker the performance of nursing care for a patient under certain conditions and directed the establishment of a list of tasks that no longer require delegation by a healthcare professional.
- **Guardianship Amendments** (HB 358, 2021) amended provisions related to court appointed guardians for minors, added situations in which a court may appoint a guardian for an unemancipated minor, and established “preponderance of the evidence” as the burden of proof for appointing a guardian for a minor.
- **POLST Order Amendments** (SB 83, 2021) updated the POLST to include designation of an agent to make health care decisions for an adult when the adult cannot make or communicate health care decisions.
- **Caregiver Compensation Amendments** (SB 63, 2021) established a program with one-time funding by which spousal caregivers who provide extraordinary care to a Medicaid waiver spouse can receive compensation for their service (up to 40 hours per week). Funding was increased in 2022 with an additional one-time appropriation to fund parents and guardians who are caregivers.
- **Disability Ombudsman Program** (HB0150, 2022) established to help adults with disabilities receive representation when needed.

### Utah State Plans

The Utah Legislature has supported statewide plans and initiatives, such as the **Alzheimer’s Disease and Related Dementias (ADRD) State Plan**. This plan, first created in 2012 and renewed in 2018, prioritizes public awareness and education activities to create a “Dementia Aware Utah” and a “Dementia Competent Workforce.” One of four ADRD workgroups especially relevant to this proposed plan for caregiving is the *Supported and Empowered Family and Other Informal Caregiver* workgroup. The ADRD State Plan has achieved meaningful positive outcomes and in 2022 significant funding was added specifically to expand in-home services and caregiver support.

Similarly, the **Utah Commission on Aging** (UCOA) was created within the governor’s office in 2010 to increase public and government understanding of the current and future needs of the aging population in Utah. The UCOA was renewed (in 2021) and successfully operates at the crossroads of public policy, research, and community services. During COVID, UCOA led the development of a new collaborative, UtahAging.org, which is a unique virtual state-wide portal for all Utahans where individuals can search for programming from many agencies across the state regardless of location. UCOA also hosts quarterly summits where representatives can announce upcoming events and share new resources. Attendance has grown to an average of 60 attending each summit, with 200+ stakeholder participants overall. Work of the Commission impacts Utahns across the lifecourse and benefits all Utahns throughout the aging journey.

The successes of the ADRD State Plan and the UCOA demonstrate how Utah has achieved meaningful impact through statewide collaboration and partnerships. A Utah Family Caregiver Plan would share synergies with these plans, but is distinct, as it would extend beyond the aging and dementia focus. It would focus on family caregivers to persons of all conditions and of all ages.



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Given the significant national-level initiatives in recent years, and Utah’s extensive previous policy efforts to support families and family caregivers, we believe **NOW is the time to create and adopt a Utah “state plan” for family caregiving.** It would provide a roadmap for future policy efforts to recognize, value, and support family caregivers in Utah.

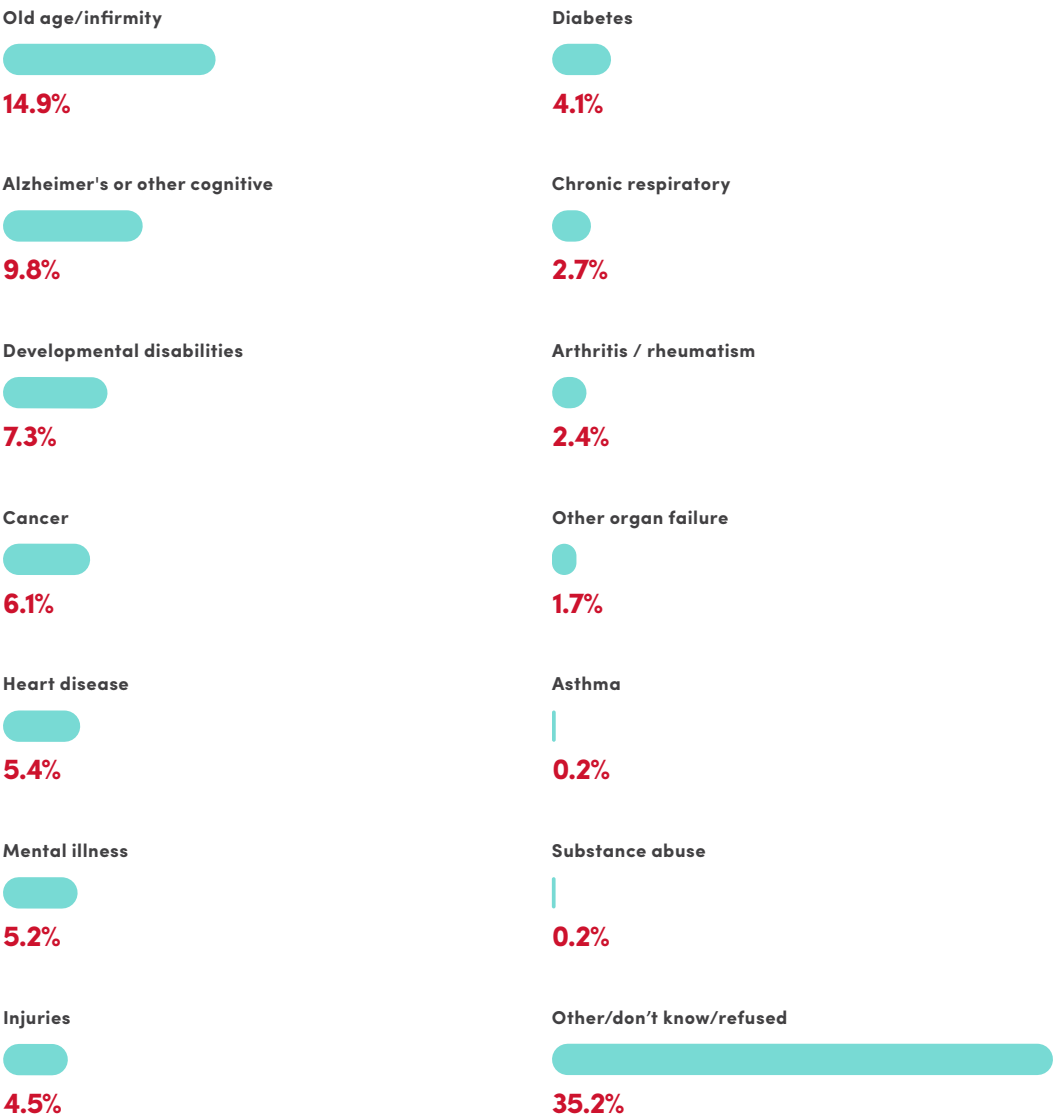
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# Utah Family Caregiver Plan: A Roadmap

The purpose of a *Utah Family Caregiver State Plan* would be to provide a consolidated and strategic approach to supporting family caregivers and recognizing the value that family caregivers bring to the state.

A plan would emphasize the importance of identifying the shared and unique needs of diverse caregivers (i.e., by age or by condition they are caring for), so that future policies and programs can be non-redundant and accessible by the many types of caregivers in our state.

Figure 3: What kinds of conditions are Utah family caregivers managing?



Source: These data from the Behavioral Risk Factor Surveillance Survey. See Appendix C for more information.

## Activities Informing the Plan

The *Utah Family Caregiver Plan*, as proposed and outlined on the next pages, was created and informed by statewide partnerships and national collaborations established by the members of the Utah Special Committee for Family Caregiving (SCFC) over the past two years. For example:

- Utah was selected by the National Alliance for Caregiving (NAC) and National Association of State Health Policy (NASHP) to be among a small cohort of states who they thought were poised to create a statewide plan to support family caregivers. Technical assistance, provided through webinars and personalized mentoring from these national organizations, was instrumental in the creation of this document.
- In drafting this document, the SCFC consulted a number of established reports. **Appendix A** provides access to the reports from 13 states that have already implemented state plans or task forces to support family caregiving in their state. **Appendix B** provides a list of reputable reports and data that describe caregiving at the national and state level.
- **Appendix C** describes three data-driven reports that describe family caregiving in Utah. These reports were commissioned by the Family Caregiving Collaborative at the University of Utah in collaboration with the Kem C.Gardner Policy Institute at the University of Utah. They provide a data-driven perspective to the needs and realities of family caregivers in Utah.
- **Appendix D** provides a list of individuals who participated in the creation of this report.
- **Appendix E** describes a Community Advisory Board of current and former family caregivers in Utah. This board was established with funds from a grant from Grantmakers in Aging. The board members provide consultation to the Special Committee for Family Caregiving and advice about how to achieve the goals and priorities of this plan from a grassroots citizen level.

## Details of the Proposed Plan

Detailed on the next pages are the products of this work – a conceptual blueprint or roadmap of how we can support the many diverse family caregivers in Utah through a coordinated state-wide approach to create policy, programs, and community awareness activities.

Listed are the proposed **goals and priorities**, along with measurable **outcomes** and suggested **tasks** of a *Utah Family Caregiver Plan*. The goals relate specifically to resources and activities that will directly support family caregivers.

Finally, we provide specific **recommendations** that are needed to implement a *Utah Family Caregiver Plan*. This Plan is intended to be implemented over the next seven years, with a reassessment of needs in 2030. Implementation can be achieved through formal legislative action or through the grassroots efforts of community organizations and individual citizens. Our recommendations highlight the importance of establishing a coordinating body to implement and monitor the progress of meeting the goals of a statewide plan.

Utah Family Caregiver Plan 2023–2030

Goals & Priorities	OUTCOME	Short Term Goal/Task (1-2 years)	Intermediate Goal/Task (2-4 years)	Long Term Goal/Task (4-7 years)
Public Awareness	Utahns will acknowledge, recognize, and appreciate the critical role of family caregivers.	Collaborate with diverse stakeholders to identify culturally appropriate language for caregivers and caregiving.	Encourage and/or develop culturally competent outreach and marketing materials.	Initiate a multi-pronged approach/campaign (i.e. with a word cloud) that applies a diversity, equity, and inclusion lens to policy, practice, messaging, and materials.
Services & Supports	Caregivers access and utilize culturally competent information and inclusive services and supports.	Engage a diverse representation of stakeholders to analyze existing resources (supports, services, and programs available for caregivers in Utah).	Collaborate with Utah Commission on Aging to house information in a centralized, accessible location.	Implement a multi-pronged approach/marketing campaign to engage caregivers with resources.
Integration into Health Care Team	Caregivers are essential members of the healthcare team.	Collect and analyze data on benefits of integrating caregivers into formal healthcare teams.	Identify best practices and tools to integrate caregivers into care decisions (e.g., <i>A Guide for Primary Care Providers: Creating Caregiver/Provider Partnerships</i> , <i>AARP</i> , <i>NIH</i> , <i>NAC’s white paper</i> , <i>VA National Campaign for Inclusive Care</i> , <i>CARE Act</i> ).	Institute a multi-pronged approach/campaign to engage caregivers, healthcare systems, and long-term services and supports.
Financial & Workplace Security	Financial security for caregivers is advanced and protected through the adoption of laws and development of workplace policies.	Engage a diverse representation of employer stakeholders to identify existing benefits and laws that support caregivers.	Disseminate culturally competent resources that inform caregiver financial decisions and future planning (e.g., to informal caregivers, employee assistance programs, human resource representatives).	Convene stakeholder advocacy groups to effect legislative changes that promote workplace and financial security for caregivers.
Data & Research	Relevant statewide data on caregiving are collected, measured/analyzed, and disseminated.	Engage a diverse representation of research stakeholders to determine data measures and needs.	Collaborate with stakeholders for on ongoing data collection and evaluation.	Disseminate data analysis to impact change, inform priorities, and advance best practices.

Recommendations for Legislative Consideration

It is recommended that this plan be supported by the following actions of the Utah State Legislature:

- 1

**Recognize and adopt** the *Utah Family Caregiver Plan* (“Plan”).
- 2

**Designate an oversight agency** to house the Plan. The Department of Health & Human Services is recommended, as they are in a position to ensure that related efforts to support families (i.e. Division of Aging & Adult Services, Juvenile Justice, Division of Services for Persons with Disabilities, Medicaid, etc.) are coordinated and non-redundant.
- 3

**Appropriate funds** to ensure the success of the Plan, including:

A.

Director salary

B.

Administrative Assistant salary

C.

Programming and activities to implement the goals of the Plan
- 4

**Create a Utah Family Caregiver Council** to implement and manage the goals of the Plan, including:

A.

Organize and convene every calendar quarter for collaboration on Plan goals and priorities

B.

Provide annual accountability report to the legislature



Appendix A. Caregiver State Plans & Task Forces

As of Summer 2022, 13 states have created and implemented state-level plans or task forces to assess and coordinate policy and programmatic activities to support family caregivers in their state.

STATE	DATE	REPORT TITLE	REPORT AUTHOR
Alabama	2017	<a href="#">A Voice for Alabama Caregivers →</a>	Alabama Caregiver Task Force
California	2018	<a href="#">Picking up the Pace of Change in California →</a>	California Task Force on Family Caregiving
Delaware	2015	<a href="#">Caregiver Support Blueprint for Delaware →</a>	Family Caregiving Task Force
Hawaii	2016	<a href="#">Report of the Legislative Family Caregivers Working Group →</a>	The Hawaii Legislative Family Caregivers Working Group
Idaho	2015	<a href="#">Caregivers in Idaho →</a>	Idaho Family Caregiver Task Force and Alliance
Kentucky	2014	<a href="#">Supports for Family Caregivers of Elders →</a>	The Legislative Research Commission
Maryland	2016	<a href="#">2016 Final Report →</a>	The Task Force on Family Caregiving and Long Term Supports
Minnesota	2017	<a href="#">Policy Brief Caregiving →</a>	The Minnesota Board on Aging
Mississippi	2014	<a href="#">Caregiver Support Blueprint for Mississippi →</a>	The Caregivers Task Force
New Mexico	2015	<a href="#">New Mexico State Plan for Family Caregivers →</a>	The New Mexico Aging & Long- Term Services Department
North Dakota	2016	<a href="#">North Dakota Caregiver Supports and Service Study →</a>	North Dakota State University
Texas	2017	<a href="#">A Profile of Informal Caregiving in Texas →</a>	The Texas Health and Human Services Commission
Wisconsin	2021	<a href="#">Task Force on Caregiving Report →</a>	The Governor’s Task Force on Caregiving

For more information:

Refer to the website “Unified Caregiving Strategy” of the National Alliance for Caregiving <https://www.caregiving.org/unified-caregiving-strategy/> to see the February 2021 report, *From Momentum to Movement: Developing a Unified Strategy to Support Family Caregivers Across the Nation* and direct weblinks to each state’s report listed in the table above.

Appendix B. Reference List

The following reference list includes the state and national surveys and reports that were consulted in the creation of the *Utah Family Caregiver Report*.

*When publicly available, full text copies of each reference can be found by clicking on the [red arrow]. If you are reading this in print format, refer to back page for a QR code to access a digital copy of this report to access the hyperlinks.*

**Caregiving (general) - National**  
[National Academies for Science, Engineering, and Medicine. \(2016\). Families Caring for an Aging America. →](#)

[Karen Marshall \(2021\). From Momentum to Movement: Developing A Unified Strategy To Support Family Caregivers Across The Nation. National Alliance for Caregiving. →](#)

[Administration for Community Living \(2021\). RAISE Act State Policy Roadmap for Family Caregivers: Public Awareness and Outreach to Family Caregivers. →](#)

[RAISE Family Caregiving Advisory Council \(2021\). Recognize, Assist, Include, Support, & Engage \(RAISE\) Family Caregivers Act - Initial Report to Congress. →](#)

[National Alliance for Caregiving and AARP \(2020\). Caregiving in the U.S. →](#)

[Stein, Judith A. and David A. Lipschutz, \(2020\). Issue Brief: Medicare and Family Caregivers. Center for Medicare Advocacy. →](#)

[Administration for Community Living, et al \(2021\). RAISE Act State Policy Roadmap for Family Caregivers: Financial and Workplace Security for Family Caregivers. →](#)

[Guengerich, Terri \(220\). State Caregiver Profiles 2017–2020 AARP Research. →](#)

[Healthy Aging in a Pandemic World: What Older Adults and Caregivers Need to Know Now. →](#)

**Caregiving (general)- Utah**  
[Utah Department of Health, Division of Aging and Adult Services. \(2022\). Family Caregiver Project. PowerPoint Presentation based on 2016 Caregiver Needs Survey.](#)

[AARP Utah \(2018\). Utahns As Family Caregivers. Survey of 801 Registered Voters Aged 40–plus.](#)

[Utah Caregiver Support Program. \(2022\). Survey results with clients.](#)

\*\* See also Appendix C for recent reports on “Utah Caregivers”

**Working Caregivers**  
[Harrington, Elizabeth and Bill McInturff \(2021\). Working While Caring: A National Survey of Caregiver Stress in the Work Force Key Findings. Rosalynn Carter Institute for Caregivers. Public Opinion Strategies. →](#)

**Grand Parents**  
[Administration for Community Living and Advisory Council to Support Grandparents Raising Grandchildren. \(2020\). Supporting Grandparents Raising Grandchildren Act: Year One Progress Report. →](#)

[Advisory Council to Support Grandparents Raising Grandchildren \(2021\). Supporting Grandparents Raising Grandchildren \(SGRG\) Act Initial Report to Congress. →](#)

[Administration for Community Living, \(2020\). Grandparents Raising Grandchildren Advisory Council Final Recommendations. →](#)

[Generations United, \(2021\). Reinforcing A Strong Foundation: Equitable Supports For Basic Needs Of Grand Families. →](#)

**Youth Caregivers**  
[Armstrong–Carter, Emma., Johnson, Catherine., Belkowitz, Julie., Siskowski, Connie., Olson, Elizabeth., \(2021\). The United States Should Recognize and Support Caregiving Youth. Social Policy Report, Vol 34, No 2. <https://doi.org/10.1002/sop2.14> →](#)

Diverse Caregivers

Diverse Elders Coalition Caring for Those Who Care, (2022). Are Diverse Family Caregivers Getting the Help They Need? →

National Alzheimer’s Association, (2021). Race, Ethnicity and Alzheimer’s In America. →

The Diverse Elders Coalition (2021). Family Caregiving in Diverse Communities: Addressing the Needs Of Diverse Family Caregivers For Older Adults. →

Bose, Mousumi, Lauren Tokarewich, Reed Bratches, and Paul Barr (2021). Caregiving in a Diverse America: Beginning to Understand the Systemic Challenges Facing Family Caregivers. National Alliance for Caregiving, National Minority Quality Forum, and Diverse Elders Coalition. →

National Resource Center on LGBT Aging, (2022). Strengthen Your State and Local Aging Plan A Practical Guide for Expanding the Inclusion of LGBT Older Adults. →

National Alliance for Caregiving (2021). Caregiving in A Diverse America: Beginning To Understand The Systemic Challenges Facing Family Caregivers. →

Caregivers as Partners in Formal Health Care Team

Dolores Gallagher-Thompson and Ann Choryan Bilbrey, (2021). Caring For The Caregiver: Incentivizing Medical Providers to Include Caregivers as Part of the Treatment Team. National Alliance for Caregiving. →

Scammon, Debra and Christy North (2019). A Guide for Family Caregivers: Creating Caregiver Provider Partnerships. David Eccles School of Business, University of Utah. →

Scammon, Debra and Christy North (2019). A Guide for Primary Care Providers: Creating Caregiver Provider Partnerships. David Eccles School of Business, University of Utah. →

Nederostek, Kate (2021). A Provider’s Guide to Caring for the Caregiver. www.utahaging.org →

Agency for Healthcare Research and Quality (n.d.). Working With Patient and Families as Advisors. →

National Alliance for Caregiving, (2021). Caring For The Caregiver: Incentivizing Medical Providers to Include Caregivers as Part of the Treatment Team. →

Veterans Affairs, Caregiving Resources

Department of Veterans Affairs. Resources for Family Caregivers →

Elizabeth Dole Foundation & U.S. Department of Veterans Affairs, (n.d.). Campaign for Inclusive Care. →

Department of Veterans Affairs Publications →

- 2015 – Patient Care Data Capture
- 2015 – Confidential Communications
- 2017 – VHA Privacy Program
- 2018 – Patient Advocacy
- 2013 – Management of Release of Information

Alzheimer’s Disease and Related Dementia

Alzheimer’s Association, (2021). 2021 Alzheimer’s Disease Facts and Figures– Special Report Race, Ethnicity, and Alzheimer’s in America. →

Alzheimer’s Association, (2022). 2022 Alzheimer’s Disease Facts and Figures– Special Report Special Report More Than Normal Aging: Understanding Mild Cognitive Impairment. →

Larson, Eric & Stroud, Clare, (2021). Meeting the Challenge of Caring for Persons Living with Dementia and Their Care Partners and Caregivers: A Way Forward. DOI: 10.17226/26026. →

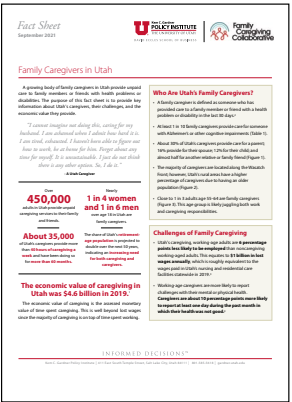
Utah Department of Health, (2018). Utah’s State Plan for Alzheimer’s Disease and Related Dementias 2018–2022. →

Utah Department of Health, (2012).Utah’s State Plan for Alzheimer’s Disease and Related Dementias Action Plan for 2012–2017. →

Appendix C. Utah Reports on Family Caregiving

The Family Caregiving Collaborative at the University of Utah commissioned a series of three reports that describe family caregiving in Utah. These reports provide a foundation of data and systematic analysis, from which to inform future policy efforts and conversations about caregiver needs in Utah.

Full reports can be found on the Family Caregiving Collaborative website: <https://nursing.utah.edu/research/groups-projects/family-caregiving-initiative> →



A two-page fact sheet describing Family Caregiving in Utah, including prevalence rates and counts of family caregivers for each Utah county.

**Authors:** Kem C. Gardner Policy Institute & Family Caregiving Collaborative at the University of Utah

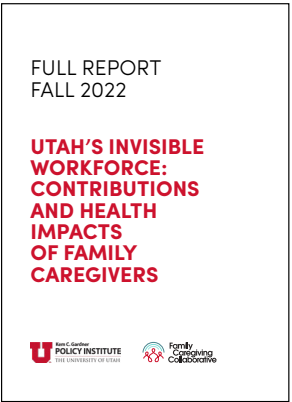
**Data Sources:** Behavioral Risk Factor Surveillance Survey, Centers for Disease Control



A report that outlines the policy ideas and shared priorities of providers and stakeholders that serve the needs of family caregivers in Utah.

**Authors:** Family Caregiving Collaborative, University of Utah

**Data Sources:** Surveys and interviews with 138 stakeholders who serve the needs of caregivers, including healthcare professionals, community-service providers, researchers, and policy advocates



A comprehensive data-driven report that describes the economic value of family caregivers in Utah, projects the number of people requiring care in Utah, and details the health and social burdens experienced by caregivers in Utah

**Authors:** Kem C. Gardner Policy Institute & Family Caregiving Collaborative at the University of Utah

**Data Sources:** Behavioral Risk Factor Surveillance Survey, Kem C. Gardner Policy Institute’s Long-Term Utah Population Projections

Appendix D. Multi-Stakeholder Caregiving Collaborative

These individuals and organizations have participated in the creation of the *Utah Family Caregiver Report*. We urge the Utah legislature to adopt this coordinated plan and/or to prioritize specific policies and programming that value, recognize, and support the invaluable contributions of family caregivers in our state.

- **Joey Hanna**
  - Executive Director, Utah Parent Center
- **Nichole Shepard and Celsa Bowman**
  - Healthy Aging Program, Utah Department of Health and Human Services
- **Janet Wade**
  - Secretary, Utah Legislative Coalition for People with Disabilities
- **Rich Foster**
  - Liaison to Volunteer Agencies, Office of Emergency Medical Services and Preparedness, Utah Department of Health and Human Services
- **Matt Hansen, MPT, DPT, MBA, BS**
  - Executive Director, Homecare & Hospice Association of Utah
- **Andrew W. Wittwer, LCSW, MPA**
  - Coordinator, Program of General Caregiver Support, VA Caregiver Support Programs, George E. Wahlen Salt Lake VAMC
- **Margene Luke**
  - Division Chair (Caregiving), Homecare and Hospice Association of Utah
- **Elizabeth Braungart Fauth**
  - Professor and Director of the Alzheimer’s Disease and Dementia Research Center, Utah State University
- **Annette P. Cumming**
  - Community Leader and Philanthropist
- **Dr. Susan R. Madsen**
  - Director, Utah Women & Leadership Project, Utah State University
- **Amy Z. Anderson**
  - Director of Outreach, Sunshine Terrace Foundation
- **Carolyn Reed**
  - Aging Services Director, Bear River Area Agency on Aging
- **Jewish Family Service of Utah**
- **Kara Dassel, PhD, FGSA, FAGHE**
  - Professor, College of Nursing & Gerontology Interdisciplinary Program, University of Utah
- **Utah Association of Area Agencies on Aging**
- **Andrea Kalvesmaki, PhD**
  - Associated Health Fellow, Informatics Decision-Enhancement and Analytics Sciences (IDEAS) Center, VA Salt Lake City Healthcare System

- **Debbie Hall**
  - Executive Director, Seniors Out and Proud
- **Sarah Scott**
  - Adult Program Director, Neighborhood House
- **Salt Lake County Aging & Adult Services**
- **Lee Moss, MS, APRN, FNP-BC, ANP-C, FAANP, FAAN**
  - Nurse Practitioner & Family Caregiver
- **Jennifer Clifton, DNP, FNP-BC**
- **Benjamin Tonga**
  - Director, Medicare Advantage, University of Utah Health Plans
- **Kathie Miller**
  - Community Leader and Philanthropist
- **Lee Ellington, PhD**
  - Director, Family Caregiving Collaborative, University of Utah College of Nursing

Appendix E. Utah Family Caregiver Community Advisory Board

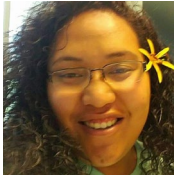
With financial support from the “Changing the Care Conversations” program funded by Grantmakers in Aging, the Family Caregiving Collaborative at the University of Utah created a community advisory board. This diverse board represents voices of the many types of caregivers in Utah. The board is receiving advocacy training (alongside caregivers from other states), has reviewed and provided input on this document, and will consult with policy makers, stakeholders, and citizens to help ensure that Utah is meeting the goals outlined in the *Utah Family Caregiving Report*.



**Michelle Creek**  
Caring for two adopted children with fetal alcohol spectrum disorder & accompanying disabilities



**Renae Hadfield**  
Mother, caring for children with Autism, Anxiety, ADHD, and Juvenile Arthritis.



**Trina Tuakoi**  
Caregiver to teenage son with spinal cord injury



**Jacqueline Moses**  
Special educator and cared for mother with Alzheimer’s Disease



**Oreta Tupola**  
Caregiver and community health worker



**Cathy Wolfsfeld**  
Cared for mother for the final 5 years of life, and 2 brothers who suffered from cancer. I also care for my grandchildren



**Jessica Mower**  
Sandwich generation – caring for a stroke survivor mother while raising two young children, all under one roof.



**Tile Fagatele**  
Cared for father and grandmother with diabetes and dementia



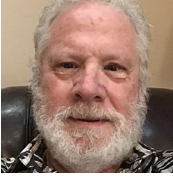
**Feli Anne Hipol**  
Daughter, cared for mother with lung cancer and father with lupus.



**Vard McGuire**  
Advocate for disability rights & brother living with sister with Down’s Syndrome



**Heather Nowlin**  
Caring for a parent who lived multiple time zones away and now in her home



**Lee White**  
Retired gerontologist and longtime caregiver to wife, at home and in nursing home



**Nia Z Sherar**  
Caregiver and world-renowned author/illustrator of the graphic caregiver narrative, *How Do I Do it Nia*



**Ulvia Guadarrama**  
Sibling caregiver, cared for sister with cancer

# Acknowledgements

The preparation of this document was a collaborative effort in which many individuals and organizations gave time, input, and expertise, with special recognition given to the core members of the *Special Committee on Family Caregiving* (SCFC), who led the preparation of this document:

- **Rob Ence**, Executive Director, Utah Commission on Aging
- **Rebecca Utz**, Senior Faculty Associate, Family Caregiving Collaborative at the University of Utah
- **Debra Scammon**, Senior Faculty Associate, Family Caregiving Collaborative at the University of Utah
- **Nancy Madsen**, past Program Manager, Utah Caregiver Support Program
- **Kate Nederostek**, current Program Manager, Caregiver Support Program, Utah Department of Health and Human Services, Aging & Adult Services
- **Alan Ormsby**, State Director, AARP Utah
- **Jeremy Cunningham**, Public Policy Director, Alzheimer’s Association, Utah Chapter

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