

# The Utah Family Caregiver Plan

*A document that outlines the needs of Utah caregivers and provides a blueprint to support Utah caregivers through policy, programs, and community awareness activities*

**DRAFT - MAY 2022**

SEEKING INPUT from STAKEHOLDERS

Please provide input via this form: <https://forms.gle/z1bVh653EiZcd2HJ8>

**2022 (or 2023-2030)**

*The Utah Family Caregiver Plan* 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.

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**, to share resources and to minimize redundancies (or siloed approaches) in the delivery of service and supports
- ❖ **Evidence-informed decision making**, including systematic collection and analysis of data, to inform and guide policy and strategy decisions



**LETTER OF SUPPORT**

This page is reserved for a letter of support from a legislative/government supporter, if and when we secure one.

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## Executive Summary

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

A caregiving role is often juggled with paid employment and other family care obligations, and extends for many years. While providing care and support 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 day-to-day activities provided by caregivers are largely unpaid, valued at nearly 5 billion dollars annually. Caregivers further reduce public and out-of-pocket healthcare expenditures by delaying institutionalization, not relying on costly at-home health care services, and lowering emergency room use among the persons being cared for. Furthermore, family caregivers play a role in alleviating the challenges associated with workforce shortages and turnover among direct-care staff of the 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, and supports them as they provide unpaid care to our most vulnerable segments of the population.

The *Utah Family Caregiver Plan* 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 and emphasizing the unique strengths and opportunities of our state. The *Utah Family Caregiver Plan* recommends a set of activities that will ensure Utah caregivers, regardless of age, relationship, or condition/illness they are providing care for, will

- 1) Recognize the important role that caregivers 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) Have financial and workplace security, and
- 5) Be supported by evidence-informed research and best practices.

The goals and recommendations of the plan will be accomplished through individual and collaborative efforts of private organizations, non-profit entities, and both local and statewide government agencies.

This plan has been developed over the last two years by a Special Committee on Family Caregiving (SCFC), with input from a broad multi-stakeholder committee. We are now seeking legislative support to implement the recommendations outlined here, which include appointment of a Director to manage and track the goals and activities of the Plan, and modest funding to maintain the Special Committee on Family Caregiving (SCFC).

### ***Caregiver (noun)***

Any relative, partner, friend, or neighbor who has a significant personal relationship with, and who provides unpaid care and support to, our most vulnerable populations, including (but not limited to) those who are aging, chronically ill, or have physical or intellectual disabilities.

These individuals may be primary or secondary caregivers. They may live with, or separately from, the person receiving care.

*Also known as*

***Family Caregiver***

***Care Partner***

***Informal Caregiver***

## Family Caregiving in Utah

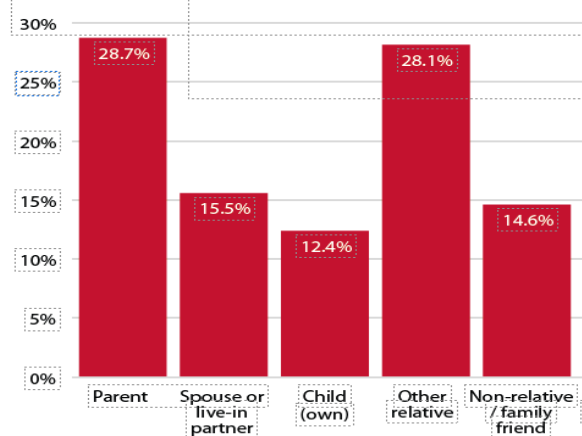
It is estimated that over 450,000 Utahns are currently caregivers, representing approximately 1 in 4 adult women and 1 in 6 adult men. Among Utahns aged 55-64, nearly 1 in 3 (29.6%) are caregivers.

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

***“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

As shown in Fig 1, 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 commonly serve as caregivers.

**Figure 1: Relationship of Recipient to Caregiver, 20**



Utah caregivers provide care for persons with a wide variety of health problems. Fifteen percent of Utah caregivers are caring 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% provide care 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 of Utah’s caregivers reported providing more than 40 hours of caregiving per week and have been doing so for more than 60 months. Caregivers commonly 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.

The economic value of the work provided by family caregivers is undeniable - in Utah, it is estimated to be about \$5 billion annually. 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.

For these reasons, caregivers must be recognized as vital members of the healthcare and long-term services and support teams for our aging and disabled community members, and caregiving needs to be prioritized as an important public health issue for Utah.

Note: All data reported here are based on the *Utah Behavioral Risk Factor Surveillance Survey*, a telephone-based sample of Utahns collected by Centers for Disease Control.

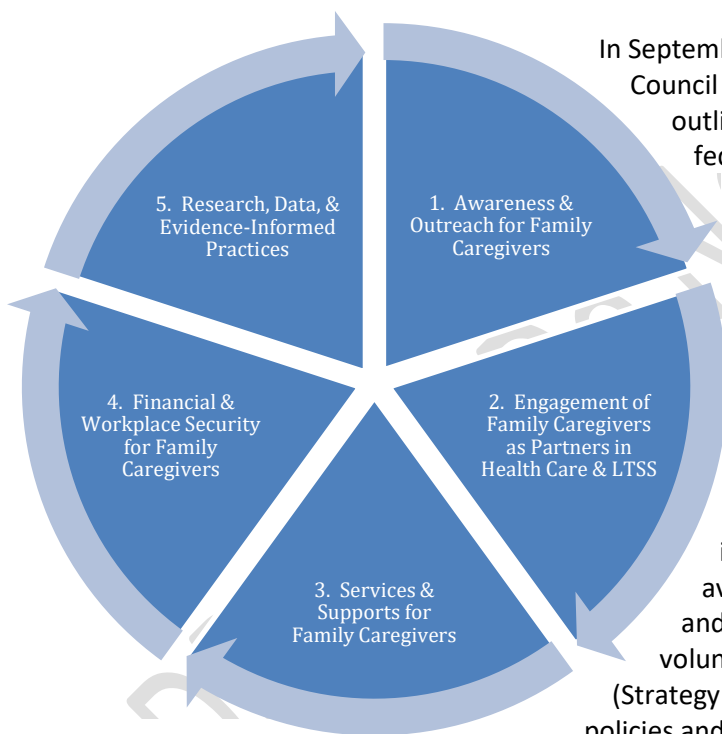
## Policies & Calls to Action to Support Family Caregivers

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 concludes with recommendations for developing a national strategy to effectively engage and support them.

Full report can be found at: <https://nam.edu/families-caring-for-an-aging-america/>

### National 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), which established and coordinated efforts to recognize and support family caregivers 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**.



### 5 Key Strategies

*RAISE National Family Caregiving Plan*

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 the image here.

The 26 recommendations included, for example, increasing public awareness and recognition of the needs, issues, and challenges of family caregivers and of the importance of recognizing and supporting them (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)

The full report can be found here:

[https://acl.gov/sites/default/files/RAISE-InitialReportToCongress2021\\_Final.pdf](https://acl.gov/sites/default/files/RAISE-InitialReportToCongress2021_Final.pdf)

## State Initiatives

As of 2022, 13 states have created and enacted a “state plan” to guide their policy activities in support of family caregivers. See Appendix A.

The National Alliance for Caregiving recently released a report called *Momentum to Movement: Developing a Unified Strategy to Support Family Caregivers Across the Nation*. This report explores the strategies followed by individual states to support family caregivers.

Examples of statewide policy efforts and initiatives are detailed in the box on the right.

Full report can be accessed here:  
<https://www.caregiving.org/unified-caregiving-strategy/>

### Examples of State Actions:

- Calls for increased legislative appropriations, such as increased funding for respite services and caregiver support programs
- Formation of caregiver advisory boards to inform policy efforts
- Collection of caregiver stories and testimonials
- Inventory of services and supports available in state for caregivers
- Expansion of tax credits or use of home-and-community based waivers (HCBS) to provide compensation for family caregivers
- Clarification of guardianship and power-of-attorney regulations to reduce elder abuse and financial fraud of vulnerable populations
- Designation of caregiver or care-partner in medical records; enhanced hospital discharge planning with care-partner
- Assessments or surveys of caregivers for purposes of needs assessment and identification of unmet needs
- Expansion of Family & Medical Leave Act (FMLA) to be more inclusive of caregiving relationships (familial and non-familial)

## Related Legislative Actions & Accomplishments in Utah

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

- ❖ In 2021 Utah established a program by which family caregivers who provide extraordinary care to a Medicaid eligible family member can receive compensation for their service (up to 40 hours per week). In 2022 this support was increased to \$11 M, acknowledging the need to compensate family members, especially those who leave the workforce in order to care for their family member.
- ❖ In 2022 the Utah legislature launched a longitudinal study on long term care.
- ❖ Patient Designated Caregiver Rule (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
- ❖ Any other policies related to abuse/fraud, that emphasize respite for DSPD, Etc??

The Utah Legislature has supported similar types of 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.” Similarly, in 2010, the *Utah Commission on Aging* was created within the governor’s office to increase public and government understanding of the current and future needs of the aging population in Utah.



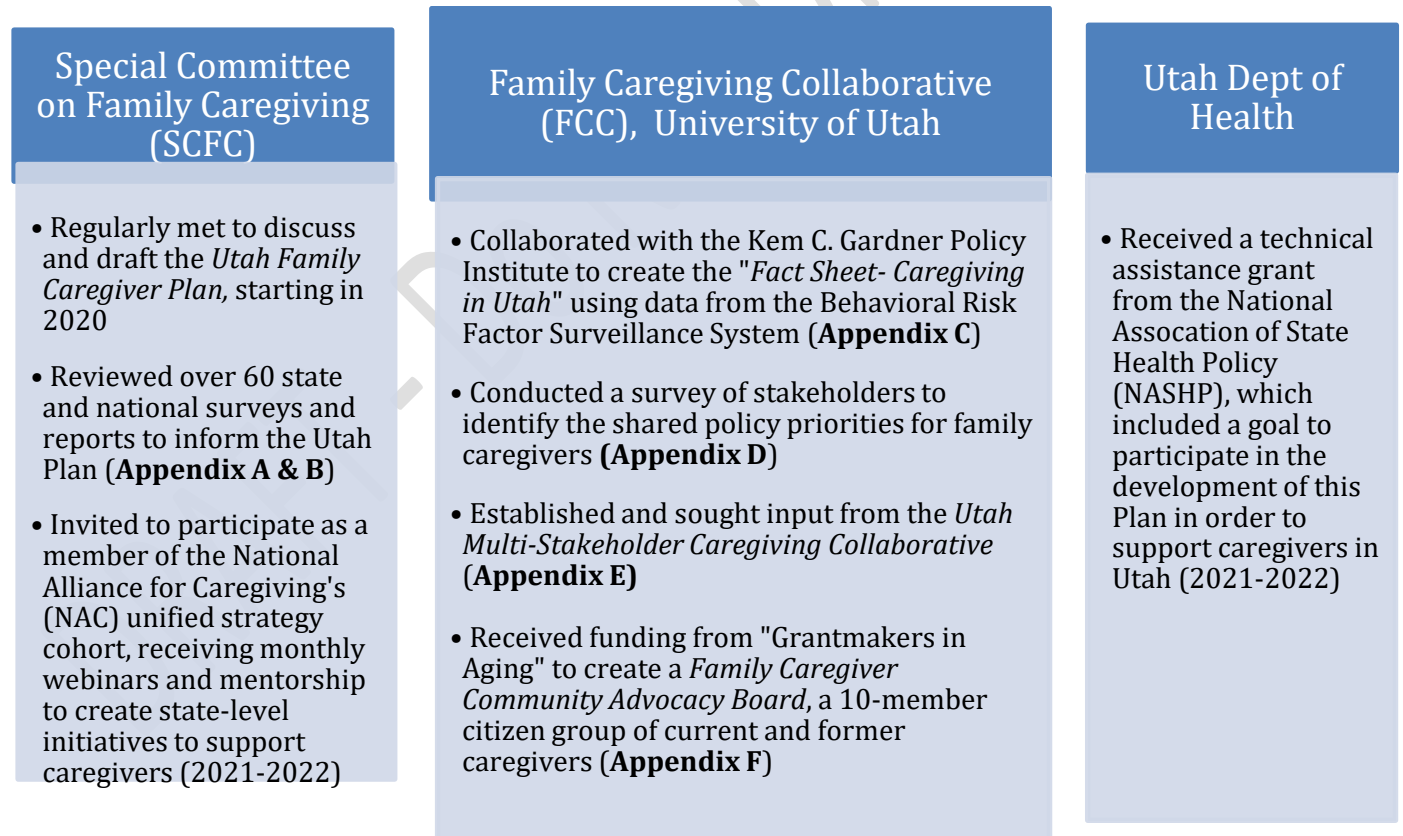
Both the ADRD State Plan and the Commission on Aging have identified caregiver support as a priority for our state.

The purpose of the *Utah Family Caregiver Plan* is to bring together the interests of diverse caregivers and stakeholders from across the state – not just those limited to aging or dementia, so that Utah can adopt a consolidated, strategic, and effective policy approach to support and recognize the value that family caregivers bring to the state. The Plan is intentionally designed to complement existing services and supports, while ensuring that resources are not redundant. The Plan seeks to bring together diverse caregivers, regardless of age and regardless of the relationship or condition of the person for whom they are caring

**Given the significant national and state level actions and strategies, including Utah’s previous policy efforts to support families, we believe that NOW is the time to expand and consolidate these types of supports for family caregivers in Utah.**

## The Utah Family Caregiver Plan

The *Utah Family Caregiver Plan* was created and informed by work and partnerships established over the past two years, including the following activities that have been foundational to these efforts:



Together these activities have informed the specific **goals and priorities**, along with measurable **outcomes** and **tasks**, and specific **recommendations** needed to implement the *Utah Family Caregiver Plan*.

## The Utah Family Caregiver Plan, 2023-2030

### Goals & **Priorities**

#### **PRIORITY AREA #1: Family members and informal support networks self-identify as caregivers.**

**OUTCOME:** Utahns will acknowledge, recognize, and appreciate the critical role of caregivers.

**Short Term Goal/Task (1-2 years):** **Collaborate** with diverse stakeholders to identify culturally appropriate language for caregivers.

**Intermediate Goal/Task (2-4 years):** **Encourage and/or develop** culturally competent outreach and marketing materials.

**Long Term Goal/Task (4-7 years):** **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.

#### **PRIORITY AREA #2: Caregivers as confident and empowered advocates.**

**OUTCOME:** Caregivers access and utilize culturally competent information and inclusive services and supports.

**Short Term Goal/Task (1-2 years):** **Engage** a diverse representation of stakeholders to analyze existing resources (supports, services, and programs available for caregivers in Utah).

**Intermediate Goal/Task (2-4 years):** **Collaborate** with Utah Commission on Aging to house information in a centralized, accessible location.

**Long Term Goal/Task (4-7 years):** **Implement** a multi-pronged approach/marketing campaign to engage caregivers with resources.

#### **PRIORITY AREA #3: Caregivers as integral partners in healthcare decisions and long-term services and supports.**

**OUTCOME:** Caregivers are essential members of the healthcare team.

**Short Term Goal/Task (1-2 years):** **Collect and analyze** data on benefits of integrating caregivers into formal healthcare teams.

**Intermediate Goal/Task (2-4 years):** **Identify** best practices and tools to integrate caregivers into care decisions (i.e. *A Guide for Primary Care Providers: Creating Caregiver/Provider Partnerships*, AARP, NIH, NAC's white paper, VA model, CARE Act, etc).

**Long Term Goal/Task (4-7 years):** **Institute** a multi-pronged approach/campaign to engage caregivers, healthcare systems, and long-term services and supports.

#### **PRIORITY AREA #4: Financial and workplace security is ensured for caregivers.**

**OUTCOME: Financial security for caregivers is advanced and protected through the adoption of laws and development of workplace policies.**

**Short Term Goal/Task (1-2 years):** **Identify** existing benefits and laws that support caregivers.

**Intermediate Goal/Task (2-4 years):** **Disseminate** culturally competent resources that inform caregiver financial decisions and future planning.

**Long Term Goal/Task (4-7 years):** **Convene** stakeholder advocacy groups to effect legislative changes that promote workplace and financial security for caregivers.

**PRIORITY AREA #5: Data/Research is utilized to inform priorities and best practices.**

**OUTCOME: Relevant statewide data on caregiving are collected, measured/analyzed, and disseminated.**

**Short Term Goal/Task (1-2 years):** **Engage** a diverse representation of stakeholders to determine data measures.

**Intermediate Goal/Task (2-4 years):** **Collaborate** with Kem C. Gardner Policy Institute and Family Caregiving Collaborative at the University of Utah on ongoing data collection and evaluation.

**Long Term Goal/Task (4-7 years):** **Disseminate** data analysis to impact change, inform priorities, and advance best practices.

**Recommendations for Legislative Consideration**

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

1. Recognize and adopt the *Utah Family Caregiver Plan* (“Plan”)
2. Authorize the creation of a Utah Family Caregiver Council to implement and manage the Plan.
3. Designate an oversight agency or Plan home. The Department of Health & Human Services is recommended, as they are in a position to ensure that related efforts to support families - for example, through Aging & Adult Services, Juvenile Justice, Division of Services for Persons with Disabilities, and Grand Families - are coordinated and non-redundant.
4. Appropriate ongoing funds to ensure the success of Plan, including funding for:
  - a. Director
  - b. Administrative Assistant
  - c. Programming and activities
    - i. Organize and convene the Utah Family Caregiver Council every calendar quarter for collaboration on Plan goals and priorities

- ii. Develop educational programming and public outreach that will meet Plan goals and priorities
  - iii. Provide annual accountability report to the legislature
5. Work with Plan Director and Council to craft policies that would establish and maintain the goals and priorities of the Plan.

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**Family caregiving is a public health priority in Utah.**

**The *Utah Family Caregiver Plan* provides a roadmap of how we can support the many diverse Utah caregivers through policy, programs, and community awareness activities.**

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## Appendix

- a. List of States that have created and implemented caregiver plans
- b. Reference of state and national caregiver surveys and reports that informed the Plan
- c. Fact Sheet – *Caregiving in Utah*
- d. Report – *Caregiving Policy Priorities in Utah*
- e. Statement of support from “Multi-Stakeholder Caregiving Collaborative”
- f. Roster of the Utah “Family Caregiver Community Advisory Board”

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## Appendix A.

### States that have created and implemented state-level plans to support family caregivers.

State	Date	Report Title	Report Author
Alabama	2017	A Voice for Alabama Caregivers	Alabama Caregiver Task Force
California	2018	Picking up the Pace of Change in California	California Task Force on Family Caregiving
Delaware	2015	Caregiver Support Blueprint for Delaware	Family Caregiving Task Force
Hawaii	2016	Report of the Legislative Family Caregivers Working Group	The Hawaii Legislative Family Caregivers Working Group
Idaho	2015	Caregivers in Idaho	Idaho Family Caregiver Task Force and Idaho Caregiver Alliance
Kentucky	2014	Supports for Family Caregivers of Elders	The Legislative Research Commission
Maryland	2016	2016 Final Report	The Task Force on Family Caregiving and Long Term Supports
Minnesota	2017	Policy Brief Caregiving	The Minnesota Board on Aging
Mississippi	2014	Caregiver Support Blueprint for Mississippi	The Caregivers Task Force
New Mexico	2015	New Mexico State Plan for Family Caregivers	The New Mexico Aging and Long- Term Services Department
North Dakota	2016	North Dakota Caregiver Supports and Service Study	North Dakota State University
Texas	2017	A Profile of Informal Caregiving in Texas	The Texas Health and Human Services Commission
Wisconsin	2021	Task Force on Caregiving Report	The Governor's Task Force on Caregiving

## **Appendix B.**

**The following sources, including over 60 state and national surveys and reports, were consulted in the creation of the *Utah Plan for Family Caregivers*.**

\*to be added later; being formatted

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## Appendix C.

Note: Full fact sheet (2 pages) will be added to document later. For now, the image is a placeholder. Click on it to be taken to a PDF

*Fact Sheet*  
September 2021



## Family Caregivers in Utah

A growing body of family caregivers in Utah provide unpaid care to family members or friends with health problems or disabilities. The purpose of this fact sheet is to provide key information about Utah's caregivers, their challenges, and the economic value they provide.

*"I cannot imagine not doing this, caring for my husband. I am ashamed when I admit how hard it is. I am tired, exhausted. I haven't been able to figure out how to work, be at home for him. Forget about any time for myself. It is unsustainable. I just do not think there is any other option. So, I do it."*

- A Utah Caregiver

Over  
**450,000**  
adults in Utah provide unpaid caregiving services to their family and friends.

About **35,000**  
of Utah's caregivers provide more than **40 hours of caregiving a week** and have been doing so for **more than 60 months**.

Nearly  
**1 in 4 women**  
and **1 in 6 men**  
over age 18 in Utah are family caregivers.

The share of Utah's **retirement-age population** is projected to double over the next 50 years, indicating an **increasing need for both caregiving and caregivers**.

### The economic value of caregiving in Utah was \$4.6 billion in 2019.<sup>1</sup>

The economic value of caregiving is the assessed monetary value of time spent caregiving. This is well beyond lost wages since the majority of caregiving is on top of time spent working.

### Who Are Utah's Family Caregivers?

- A family caregiver is defined as someone who has provided care to a family member or friend with a health problem or disability in the last 30 days.<sup>2</sup>
- At least 1 in 10 family caregivers provide care for someone with Alzheimer's or other cognitive impairments (Table 1).
- About 30% of Utah's caregivers provide care for a parent; 16% provide for their spouse; 12% for their child; and almost half for another relative or family friend (Figure 1).
- The majority of caregivers are located along the Wasatch Front; however, Utah's rural areas have a higher percentage of caregivers due to having an older population (Figure 2).
- Close to 1 in 3 adults age 55-64 are family caregivers (Figure 3). This age group is likely juggling both work and caregiving responsibilities.

### Challenges of Family Caregiving

- Utah's caregiving, working-age adults are **6 percentage points less likely to be employed** than noncaregiving working-aged adults. This equates to **\$1 billion in lost wages annually**, which is roughly equivalent to the wages paid in Utah's nursing and residential care facilities statewide in 2019.<sup>3</sup>
- Working-age caregivers are more likely to report challenges with their mental or physical health. **Caregivers are about 10 percentage points more likely to report at least one day during the past month in which their health was not good.**<sup>4</sup>

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## Appendix D.

Note: Eventually, we will put in the full report. 4 pages. This image is a placeholder for now. Click on it for a PDF copy.



## Appendix E.

## Statement of Support from members of the Multi-Stakeholder Caregiving Collaborative

We have provided input and enthusiastically support the *Utah Family Caregiver Plan*. We urge the Utah legislature to adopt this coordinated plan and to prioritize specific policies and programming that value, recognize, and support the invaluable contributions of family caregivers in our state.

- Name, organization
- Name, organization
- Name, organization

Note: In June, we will circulate next draft, and formally invite you/stakeholders to be listed as a named supporter of this document. We hope you will lend your name in support of this effort.

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## Acknowledgements

The preparation of this document was a collaborative effort in which many individuals and organizations gave time, input, and expertise. These include the many members of the *Utah Multi-Stakeholder Caregiving Collaborative* and the *Utah Caregiver Community Advocacy Board*, 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 at the Department of Health & Human Services
- **Kate Nederostek**, current Program Manager, Utah Caregiver Support Program at the Department of Health & Human Services
- **Alan Ormsby**, State Director, AARP Utah
- **Jeremy Cunningham**, Public Policy Director, Alzheimer's Association, Utah Chapter

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