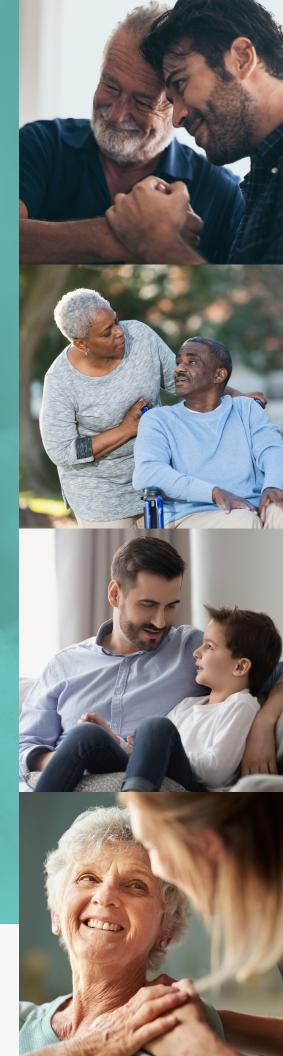
POLICY PRIORITIES TO SUPPORT FAMILY CAREGIVERS IN UTAH







Family caregivers are an essential, yet often overlooked, part of the care economy in Utah. Supporting family caregivers is a public health priority.

Family caregivers save the state significant money. They provide unpaid care to our most vulnerable populations (i.e., those who are disabled, chronically ill, or injured), allowing them to stay in their homes and community. Given the long hours and challenging work caregivers do everyday and often over many years, family caregivers commonly experience a decline in their financial, physical, social, and emotional health. This short report represents initial efforts by the Family Caregiving Collaborative to identify the needs of Utah family caregivers and the entities that support them.

Source: Family Caregiving in Utah. Fact Sheet, September 2021. Kem C. Gardner Policy Institute and Family Caregiving Collaborative, University of Utah.

450,000+

Adults in Utah provide unpaid caregiving services to their family and friends.

24%

17%

Women

18 in Utah ar

Over age 18 in Utah are family caregivers.

\$4.6 Billion

The estimated annual economic value of family caregiving in Utah

Future policy decisions should be guided by data that reflect the needs of family caregivers in our state.

To understand the needs of family caregivers in Utah, the Family Caregiving Collaborative at the University of Utah invited people from across the state to provide input about family caregivers. The survey was fielded in summer of 2021. It asked what Utah is doing well and what could be done better to support family caregivers in Utah.

Responses were received from a diverse set of stakeholders, including healthcare professionals, community-service providers, researchers, policy advocates as well as caregivers and care recipients. Over 80% of respondents had personal experience as a current or past family caregiver. Nearly half (47%) were currently providing care to a family member or friend.

Data come from 138 stakeholders, representing 13 counties.

Respondents Have Diverse Caregiving Experience

Caring for Persons of All Ages



Caregivers to children



36%



Caregivers to adults 18-64

Addressing Needs of Those with Disabilities and Chronic Conditions

19%

Physical disability

120/

Intellectual disability

19°

Alzheimer's Disease and related dementias

18%

Chronic illness

15%

Mental health

12% Autism

Living in Rural and Urban Parts of the State



17%



Urban 83%

Approximately 10% of Utah's total population lives in rural areas.

As of Fall 2021, more than 14 states, including Idaho and New Mexico, have created a formal "state plan" that prioritizes specific policy initiatives that support family caregivers in their states.

Listed in the table below are examples of the policy initiatives and actions adopted by other states. The highest priorities nationally include:

- Expanding awareness and access to existing supports and services for caregivers
- Enhancing services that allow for long-term caregiving in the home and community
- Protecting the financial security of caregivers

Respondents were asked to choose which of the policy priorities and actions they felt were "high priorities" for Utah. The top ten are listed in the Table. These data provide a blueprint for the types of policy initiatives and actions that Utah should consider as it develops its own state plan.



Utahns are united in their goals and suggestions for supporting family caregivers in the state. Responses were similar among rural versus urban respondents, researchers versus policy advocates, across one's connection to caregiving (family caregiver vs. formal care provider vs. non-caregiver) and across the age-group they were working with.

POLICY INITIATIVES & ACTIONS	% HIGH PRIORITY
Increase awareness of existing resources and programs to support family caregivers	78%
Provide access to information, education, and training for family caregivers	75%
Provide affordable and competent respite services for family caregivers	75%
Address financial well-being of family caregivers	73%
Recognize and address abuse and neglect that may occur in caregiving situations	68%
Include family caregivers in hospital discharge planning so they can provide continued patient care in homes and community	61%
Improve collaboration and minimize siloed approach to services and supports; enhance care coordination across life course and across conditions.	60%
Work with insurers and healthcare providers to prioritize and assess the needs, health, and well-being of family caregivers when they accompany patients to healthcare encounters	57%
Ensure that information/education is culturally competent and accessible to all communities	56%
Improve training for the formal healthcare workforce to work with family members in the healthcare setting	44%

There is much to do! While Utah has a solid foundation upon which to build and support family caregivers, there remains significant need.

This report draws on the collective experience of representatives from state agencies and non-profit organizations serving families, from healthcare professionals, from university faculty and researchers, and from family caregivers and care recipients. These stakeholders -- all of whom have vast experience with caregiving and/or are caregivers -- shared their insights about unmet needs and suggested possible policy solutions that could support the caregivers in our state.

Many commented on the collaborative spirit among the community-partners in Utah to support family caregivers. Respondents also noted the importance of policy work being grounded in evidence and data. The most common policy suggestions are outlined below.

There was strong consensus that Utah ought to establish a commission or task-force to assess, recommend, and implement policies that support family caregivers.

Family Caregiver

noun

A person who provides unpaid care and support to address the needs or concerns of a person with shortor long-term limitations due to illness, injury or disability.

Synonym: Informal Caregiver, Care-Partner.

PRIORITY	EXAMPLE POLICIES
Protect Financial Well-Being of Caregivers	 Provide direct financial compensation to family caregivers Allow workplace flexibility and paid time off Enact tax credits for in-home caregivers Expand eligibility criteria to include non-familial caregivers
Expand Services to Help Keep People in their Homes	 Increase access to formal respite care for all family caregivers (Respite is defined as time away from caregiving). More support services and resources for long-term caregiving, such as insurance coverage for home health aides Virtual delivery of education, support, and information
Increase Awareness and Availability of Caregiver Support Services	 Enhance outreach efforts to educate caregivers Provide a centralized service for ease of access to information, education, resources Ensure that residents in rural areas are aware of the resources available to them, including via the Internet and telemedicine





The Family Caregiving Collaborative at the University of Utah is a College of Nursing led interdisciplinary initiative whose mission is to create a future where caregivers of all ages, races, ethnicities, and gender are seen, heard, understood, valued, connected, and supported. Collaborative work focuses in 4 key areas: research, education, clinical practice, and community engagement/policy. To learn more about the Collaborative and access additional caregiving reports, visit nursing.utah.edu/FCC.

This report was produced and authored by Debra Scammon & Rebecca Utz, Senior Faculty Associates, and Amber Thompson, Caregiving Scholar, with the Family Caregiving Collaborative and graphics/design by YUMI Creative. For more information, rebecca.utz@utah.edu