

Arizona Family Caregiver  
**ACTION PLAN**

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**2025-2028**



# Planning Taskforce Participants

## STEERING COMMITTEE

**Arizona Caregiver Coalition:** Dan Taylor, Board Member; Jutta Ulrich, Ph.D., retired; Shane Allen, Board President

**Care 4 the Caregivers:** Michele Thorne, MS/CAS, Executive Director

## PLANNING COMMITTEE LEADERSHIP

**Care 4 the Caregivers:** Michele Thorne, MS/CAS, Executive Director

**Duet:** Partners in Health and Aging: Janet Richards, MA, Director of Caregiver Services

**FSL:** Erica Reyes, RN, Director of Health and Wellness

**University of Arizona, Life & Work Connections Program:** Eileen Lawless, MSW, Dependent Care Specialist

## PLANNING COMMITTEE MEMBERS

**AARP Arizona:** Dana Kennedy, MSW, Executive Director

**Ability 360:** Chris Rodriguez, MPA, Executive Director

**Alzheimer’s Association, Desert Southwest Chapter:** Tory Roberg, MPA, Director of Government Affairs

**Area Agency on Aging – Southeastern Arizona Governments Organization:** Karen Enriquez, Family Caregiver Coordinator

**Arizona Developmental Disabilities Planning Council:** Jon Meyers, Executive Director

**Arizona Coalition for Military Families:** Dee Person, Assistant Director

**Arizona State University, Legacy Corps:** Sandi Gorley, MA, Program Manager – National Project Director

**Department of Economic Security, Division of Aging and Adult Services:** Patricia Sutton, Tribal Liaison

**Family Caregiver / Elizabeth Dole Foundation Fellow:** Anne Adkinson

**Family Caregiver:** Brandilyn Coon

**Family Caregiver:** Tom Workman, Ph.D.

**FSL:** Nydia Montijo Soto, MPH, Volunteer Engagement Coordinator

**Pima Council on Aging:** Deb Seng, MA, Director of Caregiving and Community Initiatives

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**University of Arizona, Center on Aging:** Lisa O’Neill, DBH, MPH, Associate Director of Education and Policy





Family caregivers, and other informal caregivers, in Arizona make a profound contribution to community health, the state’s economy, and the well-being of countless individuals of all ages. Arizona has an estimated 800,000 caregivers<sup>1</sup>. They are among the hidden heroes in our state, providing hundreds of hours of support, often at their own expense.

For many caregivers in Arizona, the experience of assisting loved ones is deeply rewarding. A variety of public, private and nonprofit agencies and organizations in Arizona provide services and resources to support them. Still, caregivers face enormous challenges, including:

- Veteran population with unique needs,
- Growing population of older adults with physical and mental health needs,
- Growing number of individuals with cognitive decline,
- Children with developmental and physical disabilities,
- Cultural differences with language and cultural barriers,
- Rural challenges with lack of services.

This Arizona Family Caregiver Action Plan (2025-2028) has been written to address the root causes of the challenges facing our family/informal caregivers. The plan was inspired by the RAISE<sup>2</sup> Family Caregivers Act and the subsequent 2022 National Strategy to Support Family Caregivers. Initiated by the Arizona Caregiver Coalition, it is the work of a broad coalition of leaders representing dozens of organizations and agencies, and it has been informed by the voices and lived experiences of Arizona’s diverse caregivers.

The plan recommends collective action by the public, private, and nonprofit/philanthropic sectors to effect change in programs, policy, and public awareness. Work groups composed of these organizations will develop implementation strategies and identify funding. The plan is organized around three priorities:

1. **Access to Services:** Build a system of streamlined, accessible, trauma informed, and culturally appropriate services that give caregivers support on Day One.
2. **Outreach and Awareness:** Conduct advocacy and outreach that raises awareness of caregiving within the state, and shapes policy and practices in support of family caregivers.
3. **Education:** Offer comprehensive, community building, multilingual, multi-cultural education and training.

*Above all, this plan is a call for action toward the aspirational—and achievable—vision of “a resourced, resilient, statewide community of caregivers.”*

<sup>1</sup>AARP Public Policy Institute, Valuing the Invaluable: 2023 Update Strengthening Supports for Family Caregivers, <https://www.aarp.org/content/dam/aarp/ppi/2023/3/valuing-the-invaluable-2023-update.doi.10.26419-2Fppi.00082.006.pdf>

<sup>2</sup>Recognize, Assist, Include, Support, and Engage; see the Appendix for more information.



# Background

## FAMILY CAREGIVERS IN ARIZONA

Family and other informal caregivers are vital to maintaining the well-being and quality of life for many adults and children in Arizona in both familial and community settings. They provide support to individuals who need assistance with essential and everyday needs: personal care, daily living activities, transportation, and medical appointments.<sup>3</sup>

These caregivers come from all walks of life. They are parents, siblings, adult children, grandparents, neighbors and friends. They assist older adults, many of whom face mobility challenges or cognitive impairments like dementia, or look after family members, friends, and neighbors, including children with chronic health conditions or physical or developmental disabilities.

In Arizona, the role of family and informal caregivers is especially important. Our state is home to a significant veteran population, some with service-related injuries or mental health conditions. Arizona also has a significant and growing elderly population—the 12th highest per capita of any state in the nation<sup>4</sup>—who prefer to age in in their own home and community.<sup>5</sup> Arizona is home to many communities, where there is a strong cultural emphasis on family responsibility and caring for older family members. Additionally, many parts of Arizona are rural, and family and informal caregivers often provide the primary means of support and care in these regions, where professional services may be scarce or inaccessible.

## CHALLENGES

Many caregivers describe feeling deeply rewarded by the experience, including their ability to contribute to the well-being of loved ones. And while Arizona has resources and services provided by state agencies and a network of nonprofit organizations, caregivers face a variety of significant challenges in this role.<sup>6</sup>

**Lack of Self-identification** - One of the biggest challenges is that many individuals providing essential care do not necessarily see themselves as caregivers. They say “I am the spouse, the parent, the brother, the friend,” and don’t think about supports and resources they may need.

**Insufficient Access to Resources and Training** – Caregivers are often tasked with navigating complex systems including understanding complicated diagnoses, coordinating medical appointments, managing medications, communicating with healthcare professionals, managing the care recipient’s finances, and ensuring that the rights and preferences of care recipients are respected. Many family and informal caregivers do not have the background or experience to manage these challenges without feeling overwhelmed.

**Lack of Recognition** – Family and informal caregivers, as essential as they are to the health and wellbeing of millions of Arizonans, are rarely seen or treated as part of the healthcare team. This sometimes leads to caregivers being excluded from strategic planning at key governmental and community/agency levels, including hospitals.



Existing systems and a mental model that fails to recognize caregivers as vital to the state's economy and healthcare serve to perpetuate these inequities, leaving caregivers disadvantaged and resources fragmented.<sup>7</sup>

**Financial Barriers** - Caregiver needs, such as financial support, adequate respite services, and behavioral and mental healthcare, too often go unmet or the solutions are inadequate. Being a family caregiver can create high levels of financial stress. Many caregivers are forced to reduce work hours, take unpaid leave, or even quit their jobs to ensure adequate care for their loved ones, resulting in loss of income and financial insecurity.

**Mental Health** - Arizona caregivers report experiencing high levels of stress due to the extraordinary demands of caregiving, sometimes leading to anxiety, depression, and burnout. Many caregivers struggle with feelings of grief, especially if the individuals for whom they are caring have progressive or terminal conditions. Many caregivers feel isolated and alone, lacking peer support and respite services, that is, the ability to take a break from caregiving.

**Diversity** - Arizona is home to numerous ethnic communities, bringing different languages and culturally diverse expectations to caregiving. Resources and services need to take these differences into account, as well as urban versus rural settings.

*“Fundamental changes are needed in the way we identify, assess, and support caregivers. Educational and workforce development reforms are needed to enhance the competencies of healthcare and long-term service providers to effectively engage caregivers.”*

*– Journal of Palliative Medicine*

<sup>3</sup> <https://www.ncbi.nlm.nih.gov/books/NBK396398/>

<sup>4</sup> <https://www.consumeraffairs.com/homeowners/elderly-population-by-state.html>

<sup>5</sup> <https://stateline.org/2023/11/02/older-adults-want-to-age-in-place-but-their-options-are-limited-in-most-states/>

<sup>6</sup> <https://pubmed.ncbi.nlm.nih.gov/30453805/>

<sup>7</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5756457/>



# Background

## THE NEED FOR SYSTEMS CHANGE

Arizona has services and supports for caregivers, for example, through the Area Agencies on Aging, the State Veterans Services program Be Connected, or non-profit agencies. Still, many families tell of the many challenges, including all too often “I wish I had known about these services five years ago.”

Inspired by the 2022 National Strategy to Support Family, created by the RAISE Family Caregiving Advisory Council<sup>8</sup>, the Arizona Caregiver Coalition brought together organizations that serve family caregivers to draft an inclusive strategic plan. The Arizona Caregiver Coalition provided leadership and project management for this effort, with support from Care 4 the Caregivers. Grants from Community Catalyst / Grantmakers in Aging and also from Vitalyst Health Foundation and Arizona Together for Impact Fund provided funding.

More than 50 individuals representing over 25 Arizona organizations participated in planning meetings. Their work helped shape a “strategic map” that has guided this collaborative planning process and resulted in this comprehensive, statewide action plan.

## STRATEGIC MAP: ARIZONA FAMILY CAREGIVER STRATEGIC PLANNING PROCESS

### VISION

A resourced, resilient, statewide community of caregivers.

### MISSION

Collaborating to grow and strengthen systems that support caregivers from Day One.

### VALUES

- **Action:** We are strategic, pragmatic, data-driven, and persistent about making positive change on behalf of family caregivers.
- **Collaboration:** We seek to eliminate silos, share information and resources, and speak with one voice.
- **Empathy:** We are intentional about seeing and listening to others, especially family and informal caregivers.
- **Equity:** We are committed to inclusivity, seek to be culturally competent, and strive for equity and justice for all family caregivers.
- **Service:** We keep the needs of family caregivers at the center of everything we do.

### TOP PRIORITIES/GOALS:

- **Access to Services:** Build a system of streamlined, accessible services that give caregivers support on Day One.
- **Outreach & Awareness:** Conduct advocacy & outreach that raises awareness of caregiving within the state, and shapes policy and practices in support of family caregivers.
- **Education:** Offer comprehensive, community building, multilingual, multi-cultural education and training.



## Priority One: Access to Services

Build a system of streamlined, accessible, trauma informed, and culturally appropriate services that give caregivers support on Day One.

**OUTCOME #1—CAREGIVERS ARE ABLE TO EASILY FIND AND ACCESS INFORMATION ABOUT AVAILABLE SERVICES, RESOURCES, AND SUPPORT.**

### Year 1—Action Steps

- a. Create a comprehensive list of current, culturally appropriate services and resources available to Arizona caregivers.
- b. Create a list of links to existing platforms (e.g., Arizona Caregiver Coalition website [azcaregiver.org](http://azcaregiver.org), Care 4 the Caregiver website, Department of Economic Security website, the AZ 211 website and call center, the former AZ Links website, etc.) in order to link or incorporate all into a streamlined portal.
- c. Design a decision tree that helps caregivers find and access federal, state, tribal, and non-profit services.

### Years 2 and 3 —Action Steps

- a. Designate and design a centralized, streamlined, well-maintained, comprehensive online portal/website, that includes an interactive decision tree, ensuring there is “no wrong door” access for caregivers to information about available services, resources, and support.
- b. Create a training video for using the centralized portal and decision tree, and other materials designed specifically to reach diverse caregivers (such as caregivers who are deaf or hard of hearing, tribal members, etc.).
- c. Conduct outreach to every agency and organization that engages with caregivers about the centralized online portal, interactive decision tree, and training video, so they are equipped to share these resources with their stakeholders and encouraged to link to the portal via their websites.





## Priority One: Access to Services *(continued)*

**Build a system of streamlined, accessible, trauma informed, and culturally appropriate services that give caregivers support on Day One.**

### **OUTCOME #2: ARIZONA FAMILY CAREGIVERS ARE ABLE TO OBTAIN RESPITE SERVICES THAT MEET THEIR UNIQUE NEEDS.**

#### **Year 1—Action Steps**

- a. Expand the Respite Care Task Force with key stakeholders and decision makers, such as providers, agencies, and family caregivers, representing the diversity of caregivers in Arizona to:
  1. Evaluate the current process for respite eligibility, review respite service programs from other states to identify best practices, listen to and learn from the lived experience of caregivers.
  2. Develop and promote recommendations to remove the roadblocks disqualifying caregivers from getting adequate support, ensure flexibility, and improve the process. For example:
    - i. Explore the feasibility of a single form across all respite services available to family caregivers.
    - ii. Develop a shared vocabulary and list of uniformly recognized terms for caregiving and respite services.
    - iii. Expand the number of respite hours available to family caregivers through the Older Americans Act or other funding sources.
    - iv. Expand emergency resources for caregivers who have a crisis and are no longer able to support their family members.
  3. Explore ways to coordinate caregiver supports with Arizona partners that work to develop the caregiving workforce, aiming to reduce barriers to entry and improve retention in caregiving professions.
  4. Make self-directed services available everywhere that allow the family to select the paid caregiver (such as the Area Agency on Aging Friends & Neighbors program or the Arizona Caregiver Coalition Lifespan Respite).

#### **Years 2 and 3 —Action Steps**

- a. Develop an implementation and dissemination plan to ensure the recommendations of the Respite Care Task Force are implemented.
- b. Continue to work on improving the availability of Direct Care Workers (DCW).





## Priority Two: Advocacy

Conduct advocacy & outreach that raises awareness of caregiving within the state and supports systems change in support of family caregivers.

**OUTCOME #1—ARIZONANS WILL BE EDUCATED ABOUT AND UNDERSTAND THE EXPERIENCE OF FAMILY CAREGIVING, AND BE ABLE TO SELF-IDENTIFY AS CAREGIVERS.**

### Year 1—Action Steps

- a. Create an easily accessible platform for family caregivers to share their stories.
- b. Identify and describe underserved Arizona family caregiver populations, such as tribal members or caregivers living in rural areas. Identify all existing provider and agency efforts to reach these caregivers and ensure their stories are included.
- c. Work with a public relations and marketing firm to develop a multi-channel media campaign that includes the stories of diverse caregivers, focuses on the role and definition of family caregivers, and helps individuals learn how to self-identify as caregivers.

### Years 2 and 3 —Action Steps

- a. Secure funding for a statewide outreach campaign and build support in caregiver support community.
- b. Launch the media campaign targeting the general public/individuals, state leaders/legislators, educational institutions, faith-based organizations, and employers.





## Priority Two: Advocacy *(continued)*

**Conduct advocacy & outreach that raises awareness of caregiving within the state and supports systems change in support of family caregivers.**

**OUTCOME #2—OUTREACH AND SUPPORT FOR ARIZONA FAMILY CAREGIVERS IS IMPROVED BY STATE, TRIBAL, AND MUNICIPAL POLICIES AND PRACTICES.**

### Years 1-3—Action Steps

- a. Create a Caregiver Advocacy Network that will:
  1. Meet regularly to create and support an advocacy agenda that supports the work of other task forces and promotes changes in policies and practices that support family caregivers. For example:
    - i. Encourage the strengthening of partnerships between DES Division of Aging and Adult Services (DAAS), its State Health Insurance/Senior Medicare Patrol Program (SHIP / SMP), and Medicaid services.
    - ii. Shift policy and legislative requirements for the collection and reporting of data on Arizona caregivers, including but not limited to the number of caregivers served by state programs, caregivers paid, services provided, etc.
    - iii. Explore ways to collect data on caregivers, such as total number of caregivers in Arizona, hours spent on caring, or care relationships.
    - iv. Increase behavioral health services, including free in person and online mental health services, for family caregivers with mental health and substance use disorders,
    - v. Advocate for competitive pay rates for mental health counselors so that parents can access counseling through their child's Arizona Long Term Care Services (ALTCS) plan.
    - vi. Increase the amount of time refugees have access to a social worker. If they have to get their children re-diagnosed, families may be outside the 90 days of support.
    - vii. Embed caregiving and caregivers in state, tribal, and municipal planning.
- b. Provide training for caregivers on self-advocacy and story-telling in support of advocacy efforts.





## Priority Three: Education

Offer comprehensive, community building, multilingual, multi-cultural education and training for caregivers and health professionals.

**OUTCOME #1—A RANGE OF EVIDENCE-BASED EDUCATIONAL RESOURCES AND TRAINING OPPORTUNITIES WILL BE AVAILABLE TO ALL ARIZONA FAMILY CAREGIVERS.**

### Year 1—Action Steps

- a. Identify current training resources, including peer-to-peer support, resources on self-care, and caregiver-perceived needs, and identify gaps to be filled.
- b. Develop an outreach plan to raise awareness of and connect family caregivers to available training resources. Link training resources to the website resource portal in Priority 1.

### Years 2 and 3 —Action Steps

- a. Address gaps in the educational and training resources for caregivers by expanding peer support resources, caregiver training, and caregiver seminars (e.g., Partners in Leadership Training) to make them more inclusive of diverse cultures and those who are deaf or hard of hearing. Special focus should be on developing/offering resources that address:
  1. Specific caregiver groups (elderly, disabled children, veterans)
  2. Specific environments (school and workplace)
- b. Secure funding to enable tribal communities to develop their own materials about culturally relevant information to meet their community needs and build cultural competence.
- c. Work with colleges to create scholarships for family members from caregiver families to go to school for training on caregiving-related subjects.
- d. Expand vocational training for direct care workers in college and high school.

**OUTCOME #2—FAMILY CAREGIVERS WILL HAVE ACCESS TO AND USE OF FINANCIAL EDUCATION AND ADVANCE PLANNING TOOLS.**

### Year 1—Action Steps

- a. Identify current financial and advance planning education and resources.
- b. Develop “educational roadmaps” for caregiver financial strategic planning, based on specific circumstances (e.g., a child diagnosed with cancer, a parent diagnosed with Alzheimer’s, etc.).
- c. Work with health partners to ensure Medicaid patients have access to information on available financial resources, respite, eligibility for family caregiving reimbursement, and the ALTCS look-back period and accessing bank accounts of care recipients (e.g., care recipient with Dementia).



## **Priority Three: Education *(continued)*** **Offer comprehensive, community building, multilingual, multi-cultural education and training for caregivers and health professionals.**

- d. Develop and launch a plan to promote the use of the Arizona Caregiver Coalition Emergency Respite Planner.
- e. Identify other resources, including those from other states, and make them available to Arizona caregivers via the centralized portal.

### **Years 2 and 3 —Action Steps**

- a. Build strategic relationships with lawyers and financial planners that can help caregivers establish special needs trusts at discounted rates.

**OUTCOME #3— HEALTH PROFESSIONALS ARE AWARE OF THE KEY ROLE FAMILY CAREGIVERS PLAY, EDUCATED ON AVAILABLE RESOURCES FOR CAREGIVERS, RECEIVE TRAUMA-INFORMED TRAINING AND ACTIVELY ENGAGING FAMILY CAREGIVERS AS PART OF THE HEALTH TEAM.**

### **Year 1—Action Steps**

- a. Create and disseminate a list of current caregiving-related educational opportunities for health professionals (including doctors, developmental pediatricians, and behavioral health professionals).
- b. Identify and recruit members of a “Day One Task Force,” including health professionals, for the purpose of listening to and learning from caregivers, and lay the groundwork for the task force to begin working together.
- c. Create a list of caregiver resources to share with healthcare professionals.

### **Year 2 —Action Steps**

- a. Outreach to health professionals with information about the centralized online portal, interactive decision tree, and training video, so they are equipped to share these resources with clients.
- a. Convene the Day One Task Force for the purpose of listening to and learning from caregivers and address issues such as:
  - 1. Develop a plan for improving the way diagnosis day occurs for caregivers.
  - 2. Recommend actions to improve Day One, such as:
    - a. Include designated caregivers in Medical Records, treating them as a critical member of the health team.
    - a. Offer training to equip service providers, including emergency health services, to use resources like video-phone services and American Sign Language (ALS) interpreters to communicate effectively with families including factors to consider



## Priority Three: Education *(continued)* Offer comprehensive, community building, multilingual, multi-cultural education and training for caregivers and health professionals.

when working with caregivers and how to guide their care in a productive, culturally competent model for the population.

- a. Provide caregiver support on-site, including a physical space for caregivers to connect and rest while care recipients are receiving treatment.
- a. Assign/dedicate staff members who have been trained as well, to work 1:1 with families to help them book appointments, enroll in support groups, connect with the disability community.
- a. Explore a common form making it easier for caregivers to share patients' past medical history across the medical community.
3. Update and expand trauma-informed educational opportunities and resources for health professionals.
4. Review current training curricula and certification process for case workers, direct care workers, nurses, physicians, insurance providers, and others working with family caregivers, and recommend opportunities for improvement to ensure that training addresses needs of special populations (e.g., congenital disabilities, acquired disabilities, deaf/hard of hearing and Alzheimer's Disease and related dementias (ADRD)).
5. Advocate for more culturally competent, attitudinally progressive, and strength based, disability focused training in medical schools.

### Year 3 —Action Steps

- a. Build strategic relationships with lawyers and financial planners that can help caregivers establish special needs trusts at discounted rates.





# Plan Implementation

This plan cannot be accomplished by a single entity but will take collective action and collaboration between and among governmental bodies, the private sector, healthcare institutions and professionals, nonprofit organizations and philanthropy. The proposed action steps will require a combination of public, private, and philanthropic funds.

Implementation will take into consideration the existing infrastructure of caregiver supports, including the non-profit, for-profit and governmental sectors. For example, the Department of Economic Security (DES) Division of Aging and Adult Services works closely with the eight Area Agencies on Aging to provide caregiver supports, such as respite and education, addressed in the State Plan on Aging 2023-26 <https://des.az.gov/digital-library/arizona-state-plan-aging-2023-2026-english>. Work groups will also refer to the Arizona Alzheimer’s Disease and Related Dementias State Plan 2024-2029, currently being finalized.

## LEADERSHIP/MANAGEMENT

In order to ensure success in implementing this plan, an organizational structure modeled on collective impact efforts will be developed. This structure will include:

- An Action Team to steward each Priority in the plan.
- A Hub Organization to provide leadership and support for the overall plan.





## HUB ORGANIZATION

Arizona Caregiver Coalition has agreed to serve as the Hub Organization, utilizing a Project Director. Other key responsibilities of the Hub Organization include:

1. **Strategic Leadership and Vision**—Communicate a clear vision for this plan, ensure alignment of all projects with the overarching goals and objectives of the plan, and foster a shared understanding of the mission among all stakeholders and partners.
2. **Coordination and Integration**—Coordinate activities across different projects to ensure synergies and avoid duplication of efforts, facilitate communication and collaboration between action teams/task forces and other stakeholders, and act as a central point of contact for all partners involved in the initiatives.
3. **Resource Support**—Monitor the philanthropic landscape for potential grant opportunities, and partner with action teams/task forces to secure funding, where possible.
4. **Evaluation and Impact Assessment**—Develop and implement an evaluation framework to measure the impact of the plan, and track progress toward outcomes and report to stakeholders
5. **Stakeholder Engagement and Advocacy**—Build and maintain relationships with key stakeholders, including funders, government agencies, and community organizations, and raise awareness and generate support for the plan and its goals.

## ACTION TEAMS

Each of the three priorities in the plan will be stewarded by an Action Team composed of key stakeholders, decision makers, and people with lived experience. Each Action Team will select a chair or co-chairs. The following organizations having committed to leadership roles; additional partners and team members will be welcomed.

- **Priority 1: Access to Services – Arizona Caregiver Coalition**
- **Priority 2: Advocacy and Outreach – FSL**
- **Priority 3: Education – Care 4 the Caregivers**

Responsibilities of the Action Teams include:

- Taking the specific action steps leading to their outcome, as defined in this plan.
- Developing and implementing strategies and tactics to achieve those outcomes.
- Monitoring progress toward their outcome.
- Problem-solving challenges and taking action to overcome those challenges, when needed.
- Assist with identifying and obtaining funding for the implementation.



# Financial Resources Needed

In order for any plan to be implemented on a Statewide scale there must be resources directed to continue to imperative task of collaboration, communication and connections. Funding from a variety of sources will need to be obtained; the following is only a preliminary estimate. This assumes that partnering organizations can fund staff to participate on action teams from their organizational budgets.

Estimated Costs	Year 1	Year 2	Year 3
Staffing and operations	100,000	125,000	125,000
Consultants	50,000	25,000	15,000
Outreach/Marketing	60,000	125,000	165,000
Design of decision tree	50,000	20,000	20,000
<b>Total</b>	<b>260,000</b>	<b>295,000</b>	<b>325,000</b>







# Appendix

## THE PLANNING PROCESS

In 2018, the RAISE Family Caregivers Act directed the Secretary of Health and Human Services to develop a national family caregiving strategy. To support this work, the RAISE Family Caregiving Advisory Council was formed. Their work led to the 2022 National Strategy to Support Family Caregivers to support family caregivers of all ages, from youth to grandparents, and regardless of where they live or what caregiving looks like for them and their loved ones.<sup>9</sup>

Inspired by this national strategic plan, a group of leaders representing organizations that serve and or support family caregivers here in Arizona launched an inclusive strategic planning process for the state. They identified three priority areas from the national plan to focus on in order to address the most pressing needs in Arizona: Outreach and Awareness, Education, and Access to Services. The Arizona Caregiver Coalition provided leadership and project management for this effort, with support from Care 4 the Caregivers. They secured grant funding from Vitalyst Health Foundation and Arizona Together for Impact Fund and contrac

ted with an outside consultant to design and facilitate a collaborative process to create a statewide action plan in support of these three priorities. This plan will guide the work and the investment of resources for participating agencies and organizations for the next three years.

More than 50 individuals representing over 25 Arizona organizations and agencies participated in two statewide planning meetings. Special efforts were made to ensure that the group reflected the vast diversity of caregivers in the state, such as caregivers who identify as part of a particular racial, ethnic, or tribal community; caregivers who are youth or young adults; caregivers who identify as LGBTQ; caregivers who themselves have disabilities. The input gathered during these meetings was used to create a strategic map (including a mission, vision, and values for the planning process and a set of pressure-tested priorities/goals). This strategic map has served as a “North Star” for the planning process.

Three subcommittees, composed of representatives from diverse organizations and agencies, then spent six months gathering data, listening to stakeholders and those with lived experience, and identifying clear objectives and action steps. Their work has been synthesized and drafted into this comprehensive, statewide action plan.

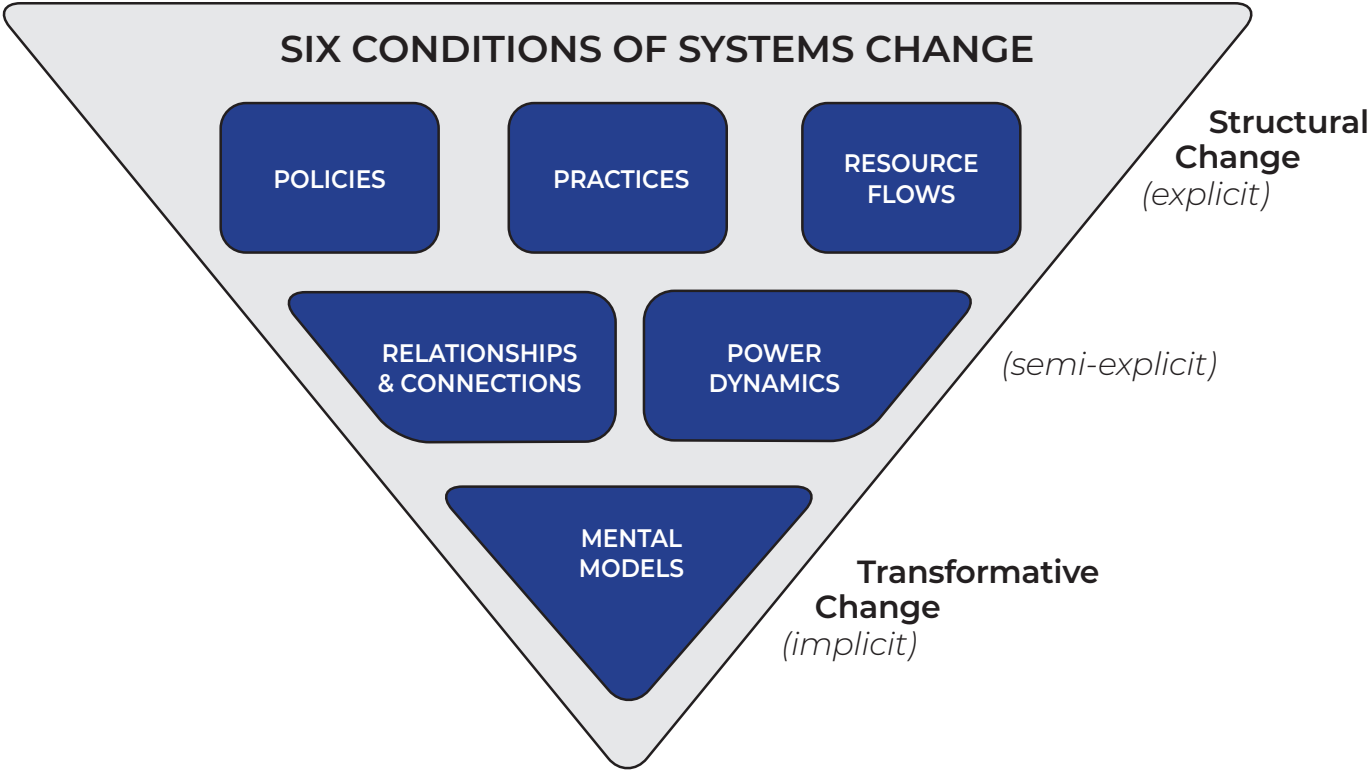
<sup>9</sup><https://acl.gov/programs/support-caregivers/raise-family-caregiving-advisory-council>



# Appendix

## SYSTEMS CHANGE MODEL

The challenges facing Arizona family/informal caregivers are widespread, complex and interconnected. This statewide action plan uses the FSG water systems of change framework<sup>10</sup> in an attempt to address the complex root causes of the problems facing caregivers and create sustainable, long-term, solutions. It seeks to create collaboration among various stakeholders, including government agencies, nonprofit organizations, and healthcare providers to advance changes in policy, practices and resource flows; strengthen the relationships and shift the power dynamics between caregivers and healthcare providers; and change the mental models that prevent government leaders, healthcare providers, the wider community, and even caregivers themselves from seeing family/informal caregivers as O’odham essential part of the healthcare team.



<sup>10</sup>[https://www.fsg.org/resource/water\\_of\\_systems\\_change/](https://www.fsg.org/resource/water_of_systems_change/)



# Thank You

## **LIST OF ORGANIZATIONS THAT PARTICIPATED IN LISTENING ("CROWDSOURCING") SESSIONS:**

- AARP Arizona
- Ability 360
- Alzheimer's Association, Desert Southwest Chapter
- Area Agency on Aging, Region One Inc.
- Arizona Caregiver Coalition
- Arizona Developmental Disabilities Planning Council
- Arizona Coalition for Military Families
- Arizona Long-Term Care Services
- Arizona State University, Legacy Corps
- Benevilla Adult Day Health Centers
- Care 4 the Caregivers
- Department of Economic Security, Division of Aging and Adult Services
- Department of Economic Security, Division of Developmental Disabilities
- Duet: Partners in Health and Aging
- Equality Health
- Family Caregivers
- Glory Days Adult Day Program
- Intertribal Council of Arizona
- Northern Arizona Council of Governments, Area Agency on Aging
- Oakwood Creative Care
- Phoenix Indian Center
- Pima Council on Aging
- Raising Special Kids
- Rosarium Health
- Southeastern Arizona Governments Organization, Area Agency on Aging
- University of Arizona, Center on Aging
- University of Arizona, Life & Work Connections
- Western Arizona Council of Governments, Area Agency on Aging

We thank Fryer & Associates for their assistance with this plan.



Mark has been caring for his partner, Lenny, who has Younger-Onset Alzheimer's. Mark and Lenny are advocates in the Alzheimer's community. Most of Mark's days consist with him monitoring Lenny's moods and activities, and being able to anticipate all of Lenny's needs. **Mark's message to fellow caregivers is to get respite, take care of yourself, and find your community of support, whether through a support group or family or other caregivers in the community.**

Nicole has been caring for her daughter Brooke for 12 years. Nicole has the following message on what she would like to see changed for Arizona caregivers: ***"I would love to see Arizona bridge the gap between caregivers who desire to give back and the systems in place that are supposed to support them but are currently underemployed. Allowing parents opportunities to volunteer with paid stipends, work temporarily, part-time, fulltime from home, in these agencies would allow caregivers the opportunity to utilize their skills outside of the home and feel the value they have."***



Betty has been caring for her mom since her dad passed away in 2017. Betty works full-time in addition to her caregiving duties. Betty has to coordinate both her work schedule and ensuring her mom's appointments are scheduled, making sure her mom has plenty of supplies on hand, and helping her mom get the memory care she needs. **Betty would like to see more funding made available to family caregivers since caregiving can be a huge financial strain.**

