

Who are Family Caregivers?

Family caregivers—unpaid relatives, partners and friends—are the backbone of Mississippi’s care system. Up to 80% of all assistance to older adults with chronic care conditions is provided by family members and friends even when there is paid help in the home. In addition to older adults, individuals of all ages and varieties of disabilities receive care from unpaid relatives, partners, and friends. For example, in 2008 about 15% of Americans aged 5 to 64 had one or more type of disability, compared to 38% of those 65 and over. Of the nearly 53 million Americans aged 5 and older with some form of disability, 30 million were between 5 and 64, and 23 million were over 65.

In Mississippi, there are over 800,000 family caregivers or about 1 in 3 households. The estimated annual economic value of unpaid care by families for Mississippi (SCC) – more than all publicly funded long-term care services combined.

17% to 35% of family caregivers see their health as ‘fair’ to ‘poor’

40% to 70% of caregivers have clinically significant symptoms of depression

Over half of the current family caregivers in the state are adult children. Almost two-thirds are holding down full or part-time employment in addition to providing an average of 20 hours a week of assistance to an older adult – typically a parent(s). Caregiving is a long-term job with the majority of families providing care for 3 years or longer. For these mostly adult children, caregiving is a juggling act between their own families, parents and work. Family caregiving is not isolated to older adults, and care may be provided for individuals of any age and level of short-term or chronic disability, including injuries and illnesses. The inclusion of individuals from all ages in the picture of those receiving care magnifies the view to consider even more caregivers whose needs reflect those of caregivers for older adults.

Why are Family Caregivers Important?

Family caregivers provide services that would normally take a multidisciplinary team to accomplish. From coordinating care to performing healthcare tasks to organizing social activities, family caregivers assume these roles, often involving complex sets of instructions or activities, with little to no training or guidance.

What Do Family Caregivers Provide?

- ✓ Medication management
- ✓ Care coordination
- ✓ Bill paying
- ✓ Wound care
- ✓ Medical equipment operations
- ✓ Health insurance advocacy
- ✓ Incontinence management
- ✓ Health decisions assistance
- ✓ Food for special diets preparation
- ✓ Personal care
- ✓ Financial management
- ✓ Household tasks
- ✓ Transportation
- ✓ Emotional & Spiritual Support
- ✓ Ostomy care
- ✓ Family member coordination
- ✓ Home test kits administration
- ✓ Social activities organizing
- ✓ Supervision
- ✓ Interpreting medical directions

Family caregivers are the largest long-term care work force in the state and nation. While use of family caregivers appears to be free to health care professionals and policy makers, it comes at a cost: poorer physical and mental health; less time for a primary caregiver to socially engage with immediate family and friends and lost productivity in the workplace. For employed caregivers who trim their hours or quit work to take care of a relative, the financial impact can be devastating: lost income, fewer Social Security credits, retirement savings deferred can mean a loss of up to \$300,000 per household.

Family and friends are needed to assist those in need across the lifespan, but shortages of family caregivers loom. Over half of family caregivers are adult children of those receiving care, between the ages of 45-64, members of the baby boomer generation. Up until now, the numbers of family members in their peak caregiving years (45-64) have kept pace with those needing the most assistance – older adults over age 80. Currently there are 7 family caregivers to 1 older adult over 80 needing assistance. But due to shrinking family size and other societal factors, by the time baby boomers will likely need assistance in 2030, that ratio will drop to 4 family caregivers to 1 older adult over 80. In 2050 when 70% of all baby boomers will likely need assistance, the ratio drops further to 3 caregivers to 1 older adult over 80.

The Demographics of Mississippi Are Changing

In the fifties and sixties, communities retooled for the wave of children born after World War II with building family communities with schools, parks, roads, recreation and library facilities. And now, those same demographics that dictate the next big wave of older adults means that communities once again must retool for aging in place.

Mississippi is aging at the same rate as the rest of the nation: there are approximately 412,454 individuals (13.9%) over the age of 65 (2010 Census). In 2030, that percentage is expected to rise to 25% or one in four individuals. One of the fastest growing age groups are those over age 75 – with an anticipated 35% increase in the next decade – a group that has the highest risk for functional impairments that required assistance.

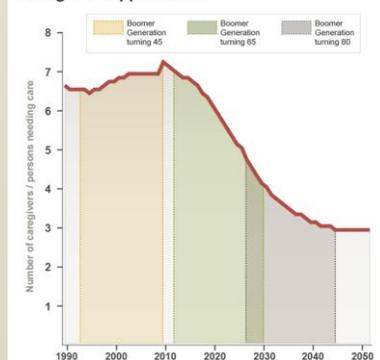
One of the most costly diseases to provide care for—Alzheimer’s disease and related dementias—is expected to almost double between 2015 and 2030. Caring for an individual with Alzheimer’s disease or other cognitive impairment extracts an especially high financial and emotional cost on the families, with estimate of upwards of \$100,000 per year for services provided by formal and informal supports. In Mississippi, there are over 51,000 individuals diagnosed with Alzheimer’s disease with an estimated 200,000+ caregivers providing care. In contrast, Autism Spectrum Disorders impacted 10, 980 children in Mississippi in

Mississippi—like all states across the country—is facing two colliding demographic challenges in the future: the dramatic rise in the number of older adults and the precipitous fall in the number of family caregivers.

You Take Care of Mom, But Who Will Take Care of You?

Family caregivers provide the majority of long-term services and supports (LTSS). But the supply of family caregivers is unlikely to keep pace with future demand. The Caregiver Support Ratio is defined as the number of potential family caregivers (mostly adult children) aged 45-64 for each person aged 80 and older—those most likely to need LTSS. The caregiver support ratio is used to estimate the availability of family caregivers during the next few decades.

Caregiver Support Ratio



In 2010, the caregiver support ratio was more than 7 potential caregivers for every person in the high-risk years of 80-plus.

In 2030, the ratio is projected to decline sharply to 4 to 1; and it is expected to further fall to less than 3 to 1 in 2050.

POLICY ACTION: Rising demand and shrinking families to provide LTSS call for new solutions to the financing and delivery of LTSS and family support.

Source: D. Redburn, L. Feinberg, and A. Houser, *The Aging of the Baby Boom and the Growing Care Gap: A Look at Future Declines in the Availability of Family Caregivers* (Washington, D.C.: AARP Public Policy Institute, August 2013). www.aarp.org/research/miss

2012, a 563% increase in the last 11 years. This disorder impacts families in ways similar to Alzheimer's Disease, other types of dementia, mental illnesses, and other disabilities by also requiring extensive caregiving responsibilities.

Like the rest of the country, Mississippi is diverse in terms of ethnicity, unequal access to services due to geography and income disparity between the wealthy and those with lower or stagnant wages employed largely in the service sector. While the aging network has acknowledged and has risen to meet some of those challenges, it is chronically under-resourced for the task and has suffered budget cuts in recent years.

Family caregivers most at risk include those who live in areas with less available services; are older spousal caregivers with their own health problems; are lower middle-income and don't qualify for Medicaid Home and Community Based Services (HCBS) but cannot afford to pay for services; are parents who must juggle between caregiving responsibilities and employment; or are living with and caring for an adult with dementia or other cognitive impairment.

What Caregiver Support Services Are Available in Mississippi?

It is important to define caregiver support services as those interventions that directly relate to the caregiver's own identified needs. Caregiver support services may include: caregiver assessment; care planning/consultation; counseling; family meetings; training on direct care skills and management of behaviors associated with cognitive impairments; benefits counseling; referral to service programs of benefit to caregivers and care recipients; information about chronic health conditions; caregiver self-care; legal and financial planning; respite; informal support organizing; support groups; and technology assessment.

Publicly funded caregiver support services in the state were funded through the National Family Caregiver Support Program (Title III-E, Older Americans Act) at \$1,286,424 last year through allocations by the Mississippi Department of Human Services, Division of Aging and Adult Services. These programs are administered by the state's Planning and Development Districts, Area Agencies on Aging. A small number of service providers provide more intensive services to family caregivers as well as information and education to an average of 535 caregivers per year under Title III-E funding.

The Mississippi Access to Care (MAC) program has been a joint effort by many public and private agencies to create a "no wrong door" approach for all who seek services, including long-term care and other supports. This effort has been under way since 2000. In October 2014, MAC designed a website, www.mississippiaccessstocare.org to be user friendly and provide access to as many resources as possible for those seeking assistance. This website will continue to be updated with resources as they become available and should serve as a comprehensive database of Mississippi services. In addition, MAC centers were strategically placed at six Planning and Development Districts (PDDs) throughout the state in order to be 'one-stop-shops' for individuals and families seeking services to find the resources needed to care for themselves or loved-ones. These centers are located in Canton, Greenville, Gulfport, Hattiesburg, Newton, and Pontotoc.

The Mississippi Division of Medicaid administers a number of Home and Community Based Services (HCBS) waiver programs that provide direct services to individuals with disabilities in their homes and communities as an alternative to nursing home care. Additionally, some of the waiver programs provide Respite Services. These services are provided as relief to the primary caregiver.

Some of these programs allow for family caregivers to receive compensation for care provided for loved ones. Being mindful of the potential for abuse that has occurred in caregiving settings, it is extremely important to screen family caregivers and provide vigilant oversight to ensure that appropriate care is being provided, especially when taxpayer funds are being expended. The table below demonstrates some of the services available through Medicaid Waiver in Mississippi.

Program	Receiving Services	Waiting List	Respite Available
Bridge to Independence (Demonstration Grant)	235	None	No
Independent Living Waiver	2,424	1,225	No
Traumatic Brain Injury/ Spinal Cord Injury Waiver	858	None	Yes
Elderly and Disabled Waiver	15,064	4,797	Yes
Assisted Living Waiver	605	200	No
ID/DD Waiver	2,132	1,781	Yes

In addition to services provided with Title III funding, there are voluntary health organizations like the Alzheimer Association, the ALS Foundation, and the Parkinson’s Association, numerous adult day programs (public and private), private care managers, home care agencies, churches, senior centers, hospitals and health centers who may provide some similar services (typically support groups and education programs). In recent years, many long-term care facilities have come forward to offer respite services within their facilities at a private pay rate that is accessible. But while reporting on the numbers served by these entities is not required, it would be safe to state that a very small percentage—likely less than 10%—of family caregivers receive any formal support from the current network within any given year.

What Are Communities Doing to Prepare For The Next Age Wave?

Around the country, communities are leading the way in innovative programs and policies with ideas that promote age-friendly communities, fund needed services, support employed caregivers, change practice within healthcare to incorporate family caregivers and look to technology for new products and services to make caregiving easier.

Efforts include creating a living laboratory for testing new services and technologies through the *Institute for the Future* in Sarasota, Florida where 32% of its residents are over age 65. Others focus on how neighborhoods can be service centers that build on formal and informal supports with the birth of the Village movement in Beacon Hill, Massachusetts.

First and foremost, any strategy related to aging in place must recognize the critical role of family caregivers and fully incorporate them as partners—and providers—in care.

Communities like San Francisco passed the [Family Friendly Workplace Ordinance \(2013\)](#) for employees who are caregivers or parents of disabled children to request a predictable and flexible schedule and prohibit employment discrimination based on the employee’s status as a caregiver or parent of disabled children.

Paid sick days legislation has passed in cities such as Seattle, San Francisco, Portland, Washington DC, Jersey City and the state of Connecticut. Paid sick days allow employees to take a paid day for their own illness or that of a family member. Only half of all employees in the U.S. have paid sick leave.

While California took the lead in passing the first Paid Family Leave Act in the country, more marketing needs to be done so employed caregivers are aware of its benefits. And nationally, some major businesses have banded together to form [ReACT](#) (Respect A Caregiver's Time) as a resource to the business community to investigate and promote best practices in workplace for employed caregivers.

Some states have added language to labor laws and human resources policies that defines Family Responsibilities Discrimination (FRD) as well as protecting workers from caregiving-related discrimination. FRD is employment discrimination that is based on workers' responsibilities to care for their family members. This type of discrimination may face pregnant employees, employees caring for aging parents, parents with young children or workers who provide care for a family member with a disability.

Other metropolitan areas have invested in changing healthcare practice such as the [Next Step in Care program](#). Developed by the United Hospital Fund and tested by 45 teams in hospitals, home care agencies, nursing home rehab facilities and hospice programs in New York City, Next Step in Care provides training and mentoring to health providers on including family caregivers in person and family centered transitional care.

Recently Rhode Island passed the [Family Caregivers Support Act \(2013\)](#) that requires a caregiver assessment that would identify problems the caregivers or care recipients might have and develop a plan to address those issues. This is required for all Medicaid funded long term services and supports in the state. In Oklahoma, The [CARE Act of 2014](#) was signed into law this year that promotes patients being able to designate a caregiver when they're admitted to any hospital and those caregivers should be notified and consulted on how to care for the patient after they go home. The CARE Act was also passed by the legislature in New Jersey and signed by the governor in November 2014. On the state level in California, legislation was passed to develop a universal assessment instrument for home and community based services in 2012. The universal assessment instrument is now in development and expected to pilot test in 2015.

Another key trend in supporting family caregivers is the rapid development of products and services to improve care in the home. Many new developments are using technology to coordinate formal and informal supports, increase and improve compliance with health maintenance tasks for chronic disease management, increase social interactions for home-bound older adults and distance monitoring of older adults in their homes. Consumer products are also undergoing a remarkable change with ageless design, improved care products that are easier to use in the home and home design for maintaining independence.

What is the Cost Benefit of Investing in Family Caregiver Supports and Services?

Changes in health care policy point to incentives that reward keeping older adults and individuals with disabilities in the community, in their home, engaged and active for as long as possible. It is also the overwhelming preference of all adults to age in place. For those older adults with chronic conditions that limit function, reimbursement incentives drive identification and care management of high-risk older adult in their homes. The desired outcome for health care is to invest in better care management in order to prevent more costly care: trips to the emergency room or hospital, use of Medicaid waiver home and community based services or placement in a nursing home.

Partnering with family caregivers and investing in assessment, care planning, skills training and interventions to decrease stress, strengthen and extend the abilities of family caregivers. Data-driven programs that utilize best practices in combination with specific interventions have begun to bend the cost curve in preventing usage of more costly public services. In Washington State, use of an in-depth caregiver assessment and consultation process has “resulted in a statistically significant delay in the use of Medicaid LTC services.” (*Family Caregiver Support Program: A Report on the FY 2012 Expansion, Aging and Disability Services Administration, State of Washington, January 2012*)

Summary

While Mississippi is known for wise innovations, the truth is that Mississippi is aging at the same rate as the rest of the country. The last 20 years have been marked by growth in the middle-aged adult population and children. The next 20 years the growth is projected for the senior population and young adults.

Now and in the future, the main providers of assistance to individuals needing assistance will continue to be family and friends . . . so now is the time to invest in the services that have shown evidence to both improve the well-being for family caregivers and for whom they care, but also to delay the movement into more costly public services. Services need to be expanded but they also need to be data driven with clear outcomes, target families most at risk and follow through with vetted models for interventions.

But even with better health care management, the silent assumption is made that there will be family caregivers willing and able to assist or provide care at home and to step in when needed for managing other life tasks for the older adult.

Half of family caregivers are in the workforce and the state needs to champion caregiver-friendly workplaces. Mississippi must be a leader in high quality family caregiver services and workplace flexibility for employed caregivers. And finally, Mississippi must lead in making sure that family caregivers are incorporated into the translation of new technologies and community developments that improve supports for the maintenance and strengthening of family caregivers. Adding these components will ensure that Mississippi will be an attractive, family-friendly place to live and work at any age.

Caregiver Supports Survey

In an effort to garner the opinions of current caregivers, the Task Force created a simple survey to send throughout the state. These opinions were gathered in written form and through the use of other survey tools. Over 100 responses were received from all corners of the state. The needs that caregivers expressed are listed in the order of most requests to the fewest by common themes: *respite for the caregiver; education for caregivers in home care; reputable/trained volunteers or paid (affordable) aides that can be called upon in times the primary caregiver is unavailable; financial assistance for caregivers who have had to leave employment for caregiving responsibilities; reduce barriers to services that require pre-authorization (mental health services, medications, day programs); and layers of services that allow for caregivers to continue to provide care while maintaining income.*

This link contains 52 responses <https://www.surveymonkey.com/results/SM-2S7LHLNL/> The other written responses are available upon request.

How Could Mississippi Increase Support For Family Caregivers in the Next Five Years?

The following recommendations are respectfully submitted to the Mississippi Legislature for consideration:

1. We recommend the establishment of a caregiver act similar to those recently passed in other states.
2. It is recommended that state, county, and local community level leaders review potential increases in resources or repurpose existing funds for targeted family caregiver services. Targeted funding meets outcome objectives for improving skills, decreasing stress and promote choice in respite options based on evidence-based and models programs that include:
 - Universal caregiver assessment and action plans to target limited resources to those most at risk and to establish outcomes for services;
 - Short term groups to decrease caregiver stress and anxiety using vetted models;
 - Skill-building classes for caregivers in direct care, decision making and management of difficult behaviors using vetted models;
 - Providing respite services across the lifespan and to all varieties of disability states that honors family choice and direction
3. It is recommended that the state initiate a plan for excellence in supporting family caregivers, similar to efforts in other states that have created state plans. Family caregivers are made up of individuals across all chronic care conditions and would benefit substantially by having an integrated approach to support caregivers across state departments and services.
4. We recommend the state create, with the support of community funders, a Blue Ribbon panel of leaders from business, services, researchers and consumers to examine the challenges and best practices to support employed caregivers and make recommendations for actions that would enable family caregivers to remain in the workforce.
5. We support going beyond the minimum requirements of the Family and Medical Leave Act (FMLA) through actions such as: Covering workers in businesses with fewer than 50 employees, expand the definition of family member, expand the use of FMLA by allowing employees to take family members to medical appointments, decrease time an employee must work before they become eligible, and increase the length of leave allowed.
6. We encourage the inclusion of family caregivers in all planning efforts and responses to federal, state and private initiatives in long-term services and supports by the state in a formalized process within the service design.
7. We recommend clarification of nursing regulations which allows nurses to delegate home care tasks to health aides, relieving family caregivers from those duties.
8. We further recommend the continuation of this Ad-Hoc Caregivers Task Force to address the study of caregiving across the lifespan in order to further explore the problems and solutions that will care for those that provide care.

About This Report

This report was commissioned by the Mississippi Legislature in the Regular Session of 2014 Senate Concurrent Resolution 561. In preparation, a literature review was conducted on research and evaluation of caregiver interventions, scaled use of caregiver assessment and services in other states, focus group and key informant interviews with service providers in Mississippi, review of local and state funding strategies for services for older adults and background study of leadership issues within the state network of aging services.

The following agencies assisted in preparing this report:

Family Caregiver Alliance
Alzheimer's Association, Mississippi Chapter
ALS Foundation of LA/MS
Epilepsy Foundation of Mississippi
American Cancer Society of Mississippi
Mississippi Department of Rehabilitation Services
Mississippi Independent Nursing Home Association

AARP of Mississippi
ARCH Respite
Mississippi Department of Human Services
Mississippi Division of Medicaid
Mississippi Department of Mental Health
Mississippi Health Care Association
National Alliance for Caregiving



Caregivers Task Force

Making Care Possible for All Mississippians