

SJR 73 – Act No. 2015-423

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A Voice for Alabama Caregivers

A REPORT FOR PUBLIC POLICYMAKERS PRESENTED BY THE ALABAMA CAREGIVER TASK FORCE

Introduction

Caregiver is not a role we ever define for ourselves, it just happens. A caregiver provides around the clock care in the home for a loved one with a disability or chronic health concern. All caregiving situations are different but they share one common “mission” which is to love, commit and support the quality of life for someone who is special in their life journey. The American Psychological Association estimates that 31% of households in the United States are involved in caregiving at any given time.

Why is this important to all Alabamians and, specifically, Alabama policymakers? Caregiving impacts:

- Long-term care and Medicaid financial stability
- Workforce labor availability and productivity
- State and federal economic wellbeing
- Individual retirement and aging-in-place options
- Caregiver physical and mental health
- Prevention of possible abuse and neglect
- The quality of life for individuals and their families

To proactively address issues as they relate to caregiving, the Alabama Department of Senior Services (ADSS), AARP Alabama, and Alabama Lifespan Respite Network (Alabama Respite) worked in partnership to gain passage of Senate Joint Resolution 73 establishing the Alabama Caregiver Task Force. This Taskforce is charged with developing a white paper on Alabama Caregiving to submit to the Governor, Legislature, and other public policy professionals. The Taskforce met quarterly for the first year and will submit the white paper in the 2017 Legislative Session. This Taskforce completed a Strengths, Weaknesses, Opportunities, and Threats (SWOT) analysis in the first meeting and worked collaboratively on gathering resources, reviewing research documents, and developing solutions to improve caregiving issues for Alabamians. ADSS also conducted six caregiver focus groups with The University of Alabama where caregivers expressed their top needs for assistance. This information is attached in Appendix 2 and 3 to show the vast challenges facing Alabama’s caregivers.

Family and friends provide the bulk of support to individuals of any age with various physical, mental and healthcare needs, although most citizens believe long-term services and supports are provided by public programs and private insurance. Studies show that 75% of the care at home is provided by informal caregivers who provide services such as meals, personal care, transportation, financial support, and housekeeping. In Alabama, limited support is provided to caregivers who qualify for Medicaid Home and Community Based Waivers, Older Americans Act, National Family Caregiver Support Program, and Alabama Respite services. While most programs focus on the care recipient, we must recognize that caregivers require support to continue to save the State and Federal Government billions of dollars in long-term care costs.

Problem Statement

*“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 a
caregiver.”*

Rosalynn Carter

Per the AARP 2015 Report *Valuing the Invaluable*, there are 761,000 caregivers in Alabama providing over 708 million hours of care, at an economic value of \$10.89 per hour, with a total economic value of **\$7.72 billion**. Caregivers are the backbone of our healthcare system and yet services to help these caregivers are limited and are not available to serve all populations, age groups, disabilities, and chronic health conditions. The Alabama Caregiver Task Force recognized there are large gaps in services for those caring for individuals with mental illness or intellectual disabilities, Alzheimer’s or other cognitive disorders, autism spectrum disorders, the returning wounded military, and those with stroke or brain injury. The services that are available are not adequately funded.

Anyone can become a caregiver suddenly and without warning, or in many situations the caregiving role evolves slowly over time. At some point in our lives most of us will experience the role of the caregiver. Present day family infrastructure is vastly different than in past decades; therefore, individuals, policymakers, and the community at large are not prepared for this phenomenon. Women who comprised most caregiving roles are now in the workforce. Institutional care is expensive and often not the family’s or individual’s choice for care. Our society is much more transient and people have moved away from their communities and natural support systems. Per a 2015 AARP Survey, the perception of women traditionally being the caregiver is changing. Forty percent of adult caregivers in the U.S. are men. Being a family caregiver for a spouse, parent, child, or any loved one takes significant time, energy, and hard work. It is very challenging. When the need happens, individuals do not know where to turn for support, and very little support is readily available in the forms of education, counseling, respite, and financial assistance. AARP documents state that more than half of all caregivers felt they had no choice in taking on this responsibility.

Alabama caregivers deserve an empathic voice; however, the AARP Scorecard ranks Alabama 50th in our nation for caregiver support. To change the perception of Alabama and to improve quality of care and long-term services and supports, there must be an organized effort to educate public policy makers and the community at-large about the growing number of caregivers and the issues that surround their daily journeys caring for their loved ones. This whitepaper gives the Caregiver Taskforce an opportunity to mobilize and strategically develop a call-to-action for public policy makers to include caregivers in their plans for future healthcare and long-term care services and supports.

Some Alabama caregivers receive minimum respite care through waivers and vouchers, leaving thousands of caregivers unable to access services. The respite care that is provided is no more than a Band-Aid approach giving a caregiver a brief break. The demand for respite and other in-home care continues to grow as baby boomers age and individuals and families choose for loved ones with disabilities and chronic conditions to remain at home versus institutional care. Because of current economic times, families are more likely to need additional supports when expendable household funds are limited. All respite providers in the state, including Home and Community-Based Waivers, National Family Caregiver Support Program, and Alabama Respite (representing other voucher respite programs) have thousands of caregivers on waiting lists.

The faith-based community, along with the community at-large, often does not realize that, though the individuals providing care are doing so out of love, it is also mentally, physically, emotionally, and financially draining. There are many ways the faith-based network can help communities utilize various resources to provide supports for caregivers. Targeting faith-based communities to assist caregivers has been a challenge for various reasons, has proven to work only in a few communities and is often started by a caregiver. Alabama Respite distributed a faith-based survey to various stakeholders targeting faith-based leadership. Thirty-five faith-based organizations statewide completed the survey. The end results concluded that faith-based organizations are unaware of the number of people in their congregations who are caregivers and they are not informed on how to provide adequate support to them. Respondents stated that planning the program was their highest area of concern, and recruiting and training volunteers was their next highest. Many faith-based organizations are also worried about the liability of providing respite without any legal immunity.

Problems with a lack of a paid workforce that is adequately trained were identified over and over by caregivers and agencies working with caregivers. This includes:

- Inadequate healthcare worker standards and certification
- Not enough home care workers identified to meet the backup needs of a family caregiver
- Inadequate and untrained case management system
- No adult day care certification

MetLife and AARP completed studies on the financial and health impacts of family caregiving. Because family caregivers do not often identify themselves as a caregiver until it becomes a crisis, they do not know where to get information or any type of assistance. Many individuals become caregivers during their peak earning years creating a negative economic impact on both themselves and their families. Caregivers often will not ask their family, friends, or their faith-based communities for help. Information empowers individuals to make informed decisions and relieves some stress, yet many caregivers say it is difficult to find assistance. A recent AARP Report surveyed family caregivers and found that only 1 in 3 (32%) had a social worker, nurse, or doctor ask if they have what they need to care for their family member, and only 16 % asked if they have what they need to care for themselves.



Who are Alabama's caregivers and why do they matter?

Alabama does not have a comprehensive long-term care system, even though there are efforts to provide home- and community-based care through the seven Medicaid waivers. Most of the support and assessment of these programs focus on the care recipient and not the caregiver or the family holistically. There are limited public dollars and they are directed towards the care recipient. In the rural areas, there are very few support services, so caregivers must function alone with virtually no support. Talking to caregivers you will find that their world is lonely, they often feel abandoned by friends and family, and that no one cares or understands.

The statistical data is alarming.

- Forbes magazine addressed Alabama as one of the nation's poorest states, with the 2016 individual median annual income of just \$41,420.
- Per Social Security, in 2016, approximately 230,951 adults and 101,845 children living in Alabama received some form of Social Security disability benefits.
- In 2015, the prevalence of disability in Alabama was 16.8%.
- Data provided by Alabama Department of Rehabilitation shows that in 2016 there were 6,316 families served with a child age birth to three in Early Intervention.
- The Department of Education in 2015 served 84,280 children with disabilities in special education.
- In the 2015 American Community Survey, the overall percentage of children with a disability ages 5 to 15 was 6.2 % or 42,900 (4.8% had a cognitive disability).
- For ages 16 to 20, 6.8 % have a disability and 5 % of these youth include a cognitive disability.
- Per the American Fact Finder, there are 65,033 grandparents taking care of grandchildren.
- Statistics taken from the 2015 American Community Survey shows the prevalence of disability for working age people ages 21 to 64 as 15.5%.
- The 2016 Annual Disability Statistics Compendium shows 796,875 Alabamians, or 16% of the population, have a disability. Of these documented individuals 18.4 % have a vision disability, 56.3 % have an ambulatory disability and 46.9% have a cognitive disability. There are 39,412 veterans ages 18-64 with a disability.
- The 2014 National Alzheimer Report shows 86,000 Alabamians were diagnosed with Alzheimer's disease.

- The CDS shows 1 in 68 children have an identified Autism Spectrum Disorder and Alabama Department of Education served 6,778 in the 2015 Child Count.
- Per the American Community Survey, the prevalence of disability of those ages 21-64 in Alabama is 14.9%, or 735,000 adults. This percent increases to 41.4% when the data includes individuals age 65+ who reported a disability.
- The Department of Mental Health served 97,908 individuals with mental illness and 5,513 individuals with developmental disabilities in 2014.

Statistics regarding the lifespan and caregiving are difficult to find, especially state specific, but what we do know is that the identified individuals mentioned above with special healthcare, cognitive, or behavioral issues of any age require the assistance of a caregiver. These Alabama caregivers assist with care if their loved one is living at home or independent in the community.



How can Alabama support family caregivers?

Numerous unmet needs of care recipients and their caregivers across the lifespan exist in Alabama; therefore, adequate relief from caregiving responsibilities must be addressed as a priority for long-term care systems change. Educating policymakers on the issues as they relate to caregiving is an advocacy effort by this task force to facilitate change.

Identified ways policymakers can aid and support family caregivers:

1. Effectively develop, test, and implement Medicaid and other state-funded programs to ensure that caregivers are identified, their needs assessed, and they are supported in the delivery of educational programs, healthcare, and long-term services and supports such as counseling and respite.
2. Provide support to strengthen the training and capacity of healthcare and social service providers/case managers to provide caregivers with evidenced-based supports, information regarding benefits, and local services in the community.
3. Explore, evaluate, and, if warranted, adopt legislation and/or policies to provide support for working caregivers such as flexible working schedules, paid leave, and financial or legal assistance.
4. Expand data collection infrastructures to determine the number of individuals with long-term chronic mental/physical health diagnoses, such as autism and dementia-related diagnoses, and the number of caregivers in Alabama to assist policymakers with future planning and advocacy efforts for the provision of adequate services and supports.
5. Address the issues related to a lack of direct care workers, especially in the rural areas of the state.
6. As the State Medicaid Agency moves into managed care, ensure that all policies and regulations will include family- and person-centered approaches to care and that high-need individuals are assisted with the provision of services that are not in existence.
7. Encourage healthcare plans to recognize and gain feedback from family caregivers as their involvement can ensure better quality of care.
8. Support care coordination and services provided through the Aging and Disability Resource Centers (ADRCs) “no wrong door” approach for helping members to navigate the health and long-term services and supports system, providing information, assistance with public benefits and applications for services, access to community-based resources, and follow-up.
9. Support the Alabama Lifespan Respite Resource Network (Alabama Respite) to provide caregiver training and person-centered voucher respite.
10. Ensure that family caregivers who provide medical and nursing tasks have adequate opportunities to learn how to administer medications and injections, provide wound care, and perform other kinds of complex medical and behavioral healthcare.
11. Provide caregivers access to other support services such as home modifications, assistive technologies, other support services, and transportation.
12. Implement recommendations in the State Plan developed by the Alzheimer Taskforce.

The 65+ population in Alabama grew by 16% from 2010-2015 and is projected to increase by 50% from 2015-2040.

13. Eliminate long waiver waiting lists for home- and community-based services that force families into crisis before they can get any assistance.
14. Require health and human service agencies to work together in providing person and family centered services and a unified approach to resolve issues and facilitate change.
15. Establish a Taskforce to review the number of caregivers who are aging out/dying with no resource in place for their care recipient who has been their dependent. Develop a plan and care solutions.

Economic/State Benefits

The 65+ population in Alabama grew by 16% from 2010-2015 and is projected to increase by 50% from 2015-2040. These numbers alone show the need for adequate planning for this surge in individuals requiring long-term services and supports. Caregivers in Alabama are providing **millions of hours** of unpaid care, saving the State and Federal Government billions of dollars in healthcare-related costs. Consequently, the extent and nature of the need for caregiver support services such as respite is evidenced by the fact that Alabama caregivers provide approximately 80% of all long-term services and supports for family members. These caregivers provide over 700 million hours of unpaid care at home. The market value of this unpaid homecare is over \$8 billion dollars per year. As the state moves to Managed Care, these plans have a strong financial incentive to consider how to serve the family caregiver to better care for the care recipient and improve quality, therefore saving cost of overall care. Helping to support the family caregiver from becoming ill or burned out can delay or prevent costlier placement in a nursing home.

Finding a way to expand a “lean” and “fragile” budget that addresses caregiver support in long-term care cannot be the only solution to these problems. Communities encouraging participation of faith-based communities and businesses to assist with private solutions must be addressed or the benefits of caregivers may subside. Particularly in the South, policymakers and often community support systems see caregiving as a traditional family value of “you should take care of your own,” yet that is an unrealistic expectation given the family structure and dynamics as it is today. Creating solutions to support individuals living at home and their caregivers is the most effective and efficient method to provide long-term care services and supports, as evidenced already by the billions of dollars saved by caregivers who receive little appreciation, support, or understanding. When there is support, there is hope.

Summary

Caregivers not only help older people and others with disabilities to remain independent and in their own homes, but they also reduce unnecessary hospitalization and Medicaid-funded long-term care such as nursing homes and intermediate care facilities. Institutional care is very costly to the General Fund budget and supporting caregivers is a front-end cost that will save money in the long term.

Caregivers are heroes who often compromise their own health and finances. They provide complex medical tasks with little or no training. This paper is a plea to all policymakers to help change our culture of providing long-term care and supports to a more person- and family-centered approach for long-term services. Supports that include the caregiver in the assessment of needs and preferences and that are team focused within the care planning process result in a more cost effective and quality service delivery.

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Acknowledgements:

The Alabama Legislature

Neil Morrison, Commissioner, Alabama Department of Senior Services

The Staff of Alabama Lifespan Respite Resource Network

The Staff of AARP Alabama

Family caregivers who participated in the Caregiver Focus Groups

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This white paper was paid for with Grant funds from The Administration of Community Living/ Administration on Aging.



Call to Action for Legislative Support of Caregivers:

- CARE Act: Lawmakers are encouraged to enact the Caregiver Advise, Record, Enable (CARE) Act to help family caregivers and their care recipients enter the hospital and be successfully transitioned back home. The Care Act requires hospitals to:
 1. Record the name of the family caregiver on the medical record of their loved one.
 2. Inform the caregiver when the patient is discharged.
 3. Provide the family caregiver with education and instruction of the medical or nursing tasks they are being asked to perform for the patient at home.
- Family Caregiver Legislation: Many state legislatures have enacted laws that address workplace flexibility, allowing family members to care for their loved ones without the fear of losing their jobs; have expanded guardianship and power of attorney to allow caregivers to make critical medical decisions on behalf of a family member who is ill; and have expanded authority for nurses to continue to support caregivers and their care recipients.
- A Good Samaritan Law: Civil Immunity Law: Legislators are encouraged to pass HB 175 in the 2017 Legislative Session to extend the Alabama Good Samaritan Law to include volunteer caregivers in the list of entities protected by law when acting in good faith to the best of their abilities to provide care for an individual with a disability or chronic health condition.
- Increase Funding for Caregiver Services: As state funds become available, increase budget allocations for respite, training and other caregiver services in support of Alabama's family caregivers who serve as the primary provider of long-term care for many individuals with disabilities and chronic health conditions.

Appendix 1

Resources

- U.S. Census Bureau, 2010 Decennial Census
- U.S. Census Bureau, 2014 American Community Survey 1-Year Estimates
- 2015 Disability Status Report- Alabama/C 2016 Cornell University, www.disabilitystatistics.org
- Rehabilitation Research and training Center on Disability Statistics and Demographics, Annual Disability Statistics Compendium, 2016, www.disabilitycompendium.org.
- Together Success, 2016 Alabama Department of Rehabilitation Services, Annual Report, www.rehab.alabama.gov
- American Psychological Association, Who Are Family Caregivers? www.apa.org
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- Susan C, Reinhard, Wendy Fox-Grage, and Lynn Friss Feinberg, AARP Public Policy Institute, Family Caregivers and Managed Long-Term Services and Supports, Research Report, November 2016, www.AARP.org/ppi
- Jean Accius, PHD, AARP Public Policy Institute, Breaking Stereotypes: Spotlight on Male Family Caregivers, March 2017,
- Alabama Department of Mental Health, FY14, Annual Report, www.mh.alabama.gov
- Ewing, Joshua, *Legisbrief*, National Conference of State Legislators, Supporting Family Caregivers, Vol.23, No. 10
- The MetLife Study of Caregiving Costs to Working Caregivers, Double Jeopardy for Baby Boomers Caring for Their Parents, June 2011, www.MatureMarketInstitute.com
- The National Alliance for Caregiving and the AARP Public Policy Institute, Caregiving in the U.S. 2015., www.AARP.org/ppi
- Michael Sentence, J.D., LL.M., Alabama State Department of Education, 2016-2017 Quick Facts, February 2017
- Census Bureau Median Family Income by Family Size (Cases Filed Between November 1, 2015 and March 31, 2016, Inclusive)
- Social Security Administration, Alabama Congressional Statistics, 2016, www.socialsecurty.gov/policy
- State of Alabama, ACES. Data Collection, October 2015, Child Count.

Appendix 2

SWOT Analysis
Caregiver Programs and Supports for Alabama
Completed 8/20/15 by the Alabama Caregiver Task Force

Strengths	Weakness
<ul style="list-style-type: none"> • Taskforce members here to influence policy • Legal awareness by passing SJR73 • Work of Lifespan Respite over the years • Patchwork of assistance • Family support groups by designated groups • The strength of family caregivers • Faith-based interest • We all will experience in our lives some way being a caregiver • 2 more years of LR funding • Regional offices MR/DD • HHS infrastructures • Health Human Service agencies communication and partnerships • Caregivers at the table • Resources in educational community • Family support-passionate-low money-good help • Opportunity to get information out with collective list • ADRCs (Aging and Disability Resource Centers) “no wrong door” • AARP Prepare to care national coordinator/Alabama specific • Bring in more chronic health, self-prevention programs 	<ul style="list-style-type: none"> • Family resources/support for head injury • No adult day care certification • Financial ruin • Low natural supports • No healthcare worker certification/standards • Not adequate qualified backup home care help for family caregiver • Family supports separated in money, programs, and communication • Family caregivers do not identify as caregiver and they do not know of services • Caregivers do not ask for help • Unemployment issues for family and paid caregivers • Not awareness that many times it is grandchildren taking care of grandparent • Lack of insurance (average/TA/caregiver support) • Lack of communication to some people in their homes, isolation • Families do not stay in one place anymore • Inadequate/untrained case management system • High need groups with no services • Alzheimer taskforce-report stalled • Lack of way to connect people to the right resource/barriers they experience • Family has no way to review what resources available • Not using educational resources to expand opportunities for high school students to increase health workforce • Caregivers don’t call until a crisis • Caregivers do it all-never ask for help for fear of what will happen • Waiver wait list forces families into crisis before they get help • Not a long-term plan • Lack of support from policy makers • Access to information and services • Connecting people to the wrong resource • Gaps in resources for severe disabilities and behavior issues • No autism waiver

SWOT

Opportunities	Threat
<ul style="list-style-type: none"> • Connecting people to resources that are available • A qualified paid caregiver registry established • Junior college certification/career path/training • Changes-RCO, LRC, etc. and advocating for caregiver support • Faith-based support • Win-win situations among all financial interests working/advocating together • Healthcare groups providing support • To drill down what resources, we have and share • Unified way to address issues • A campaign to reach out to caregivers “encourage them to ask” for help • Health and Human Service system has opportunities with growth • Job readiness • Individual family support-utilize-expand resources • LTC facilities expansion of support to caregivers • Assistive technology • Online training for caregivers/more broadband • Better training for case management/focus on • Understanding role as caregivers, providing support for caregivers • Pulling a resource base together that is accessible/friendly/known to public • High school program-that leads to useful paid employment and further education opportunities • Educate caregivers about resources. • LRC planning to include caregivers supports/education • AARP Prepare to care/train all end of life issues • This taskforce ability to make systems change • RCO/LRC will need resource development/collaboration for access • RCO/LRC need good case management support • Greater coordination/use of Education/community college curricula for support 	<ul style="list-style-type: none"> • Caregivers aging out • No resources for gap populations with severe disability and behavior issues • Not enough paid/trained caregivers • Quality of information for caregivers and care recipients • Family units falling apart • Financial interest conflicts • Legislature not acting on budget responsibly to solve health care and social service issues • more healthcare going to cost more money • More in numbers put in institutional LTC than in Community based • Abuse and neglect • Numbers over 65 increasing dramatically • Caregivers aging out/dying with no resource for care recipient • Not asking for help leads to big problems • Policy makers/legislature do not understand the issues of caregiving • Caregivers stopping what they do and shifting their burden on the state/federal government out of lack of support- lost billions. Walking away from Caregiving. • A generation who does not care

Appendix 3

Alabama Caregivers Talk about Their Needs

To characterize the needs of Alabama caregivers, the Alabama Department of Senior Services (ADSS) and the Alabama Research Institute on Aging (ARIA) of The University of Alabama partnered to conduct a series of focus groups with family caregivers. Participants were asked to give their opinions on what the top issues facing Alabama caregivers are, and what measures might be taken to help meet those needs. In all, six of the seven Congressional Districts were represented; scheduling problems prevented completion of the group in District 1.

Sample characteristics. Table A shows characteristics of the 63 caregivers who participated in the focus groups. Reflecting national data, focus groups were predominantly female and ranged in age from 31

Table A. Characteristics of focus group participants

	N (%)
Female	48 (76%)
Male	15 (24%)
African American	35 (56%)
White	27 (43%)
Other	1 (1%)
Current caregiver	47 (77%)
Former caregiver	14 (23%)
Live with care recipient?*	
Yes	42 (68%)
No	19 (32%)
	M (SD)
Age	63.8 (9.6)
Years as a caregiver	6.5 (5.5)
NOTE: Numbers may not sum to 63 because of missing responses on some items.	
*Now or in the past	

to 82 years. Respondents were disproportionately African American, mainly because of recruitment differences at different sites. A broad range of caregiving experience was represented: one respondent had been providing care for only one month, another for more than 30 years. Of the 58 caregivers who answered our question about relationship to the care recipient, half provided care to their mothers; a third cared for a spouse. Six had cared for multiple family members and/or friends either currently or in the past. Notably, several participants were professional as well as family caregivers.

Care recipients suffered from a variety of health problems, and most had multiple chronic illnesses. Alzheimer’s disease or other dementia was the most common, cited by two in five (39.7%) of focus group participants. Other problems for which respondents provided care included stroke, mobility problems and “old age” (14.2% for each), heart problems and arthritis (12.7%), diabetes (9.5%), hypertension (7.7%), and cancer (6.3%).

Identified concerns: Each focus group was asked to list the major issues or concerns facing family caregivers. No further instructions were given, but groups were reminded that the focus should be on concerns that the State of Alabama might help address. Although each group

expressed some unique concerns, a number of common themes emerged. Table XY summarizes the 10 broad issues that were noted by at least two of the 6 focus groups.

The most commonly cited issues facing family caregivers, each raised in 5 of the 6 groups, were financial burden, need for respite, and concerns about the caregiving workforce. Discussion of **financial burden** addressed the costs of providing informal care and the need for affordable services and programs. A common theme was the lack of support for middle-class caregivers, whose loved ones may not qualify for services through Medicaid or other means-tested programs. Several groups called for review of healthcare financing to identify changes that could relieve the financial burden faced by family members. Others noted the need for information and assistance in financial planning, not only for long-term care but also for everyday “incidental” costs such as purchasing continence care supplies or other needed items. Several participants noted that the latter, everyday costs often come as a surprise to caregivers, and can represent a substantial budgetary strain.

Respite care was also identified by 5 of the 6 groups as a pressing concern. Caregivers emphasized the need for rest and relief at two distinct levels: not just an occasional “vacation” from caregiving, but also daily respite to take care of routine household business and other family concerns. Both forms of respite—personal time on a daily basis as well as an occasional “real break” from the stresses of care provision—were strongly valued. Focus group participants praised currently available respite programs, including adult day care programs. However, caregivers emphasized that these services need to be expanded and enhanced to meet caregivers’ daily needs, e.g., through in-home respite programs.

Concerns about the **professional caregiving workforce**, raised by 5 groups, centered on the availability of affordable, quality professional care. Several groups decried the lack of “good help” in daily care. Patience and caring attitudes are highly valued in paid caregivers, but professional training is sometimes lacking. Dementia care was noted as a specific training priority for professional caregivers. Affordability was a second strong theme with regard to the caregiving workforce, reflecting concerns about the financial burden of family care outlined above. One group raised the question of licensed vs. unlicensed help, as a trade-off of skills vs. affordability.

Table B. Top 10 concerns of family caregivers in Alabama

Topic	Number of groups
Financial burden	5
Respite	5
Workforce / paid care	5
In-home care	4
Long-term care planning	4
Information needs	3
Stress	3
Caregiver support	3
Environmental support	3
Other specific needs	3
Findings from six focus groups conducted throughout the state of Alabama, Sept.–Nov. 2015	

In-home care (4 groups) was identified as a key contributor to caregivers' ability to keep their loved ones at home. Home care was clearly preferred over institutionalization not only on financial grounds, but also to preserve quality of life of the care recipient. This issue was closely related both to financial burden, particularly the affordability of home care, and to workforce issues, in terms of the quality of home care services currently available. One respondent stressed that in-home medical care also helps relieve family member's caregiving burden, stating that it took 2-3 hours just to prepare her care recipient to leave the house for a medical appointment.

The next two themes addressed need for caregiving information. A diverse group of concerns, voiced by 4 of the 6 groups, converged on **long-term care planning**. A first subtheme was the importance of personal planning, particularly being prepared to make changes in one's own lifestyle to accommodate care provision and the care recipient's needs. A second was advance care planning. Here, respondents specifically mentioned legal issues and the need for caregiver information on legal competency, advance directives, end-of-life care and other aspects of medical decision-making. Finally, two groups emphasized the importance of communication with other family members in planning informal care.

Broader **information needs** of family caregivers were described by 3 groups. Emphasis here was on accessible, easy-to-find information about caregiving generally as well as available services and how to obtain them. A subtheme was the need for specific information and skills training, for example, in how to use durable medical equipment or specifics of home care following care recipients' discharge from hospital.

Although **caregiving stress** was discussed specifically by only 3 groups, it was a strong underlying theme in all 6. In two groups, the first response to our initial question, "What are the issues facing family caregivers?" was a resounding, "It's stressful!" Specific sources of caregiving stress include the time and energy involved in direct care provision, dealing with role reversal (being "the parent to my parent"), and the care recipient's resisting care from family or paid caregivers. Other family members were also cited as a source of stress; here, the emphasis was on improving communication within the family to improve quality of life for both the primary caregiver and the care recipient.

Caregiver support was identified as a strong need by 3 of the 6 groups. This theme was distinct from that of information needs in that it emphasized **emotional** support for dealing with the stresses of care provision. In addition to traditional caregiver support groups, respondents suggested in-home support, including one-on-one contact and volunteer assistance, as potentially helpful programs. "Village-to-village" community support was also cited as a valuable resource.

A final specific theme was **environmental support** (3 groups). A first major need was for help in obtaining durable medical equipment, particularly items that are not traditionally supported by Medicare or Medicaid, and for which rentals may not be available (e.g., walk-in tub). Such items were valued not just to improve ease of care, but to help prevent falls or other accidents. Similarly, accessible and affordable housing was cited as a key to keeping frail care recipients living independently in the community.

A last category comprises a series of **specific needs** identified as potentially improving caregivers' ability to provide care and to weather caregiving stress. Some examples are senior companion programs, nutrition programs (particularly home-delivered meals), and pet care for recipients' pets. Caregivers also spoke cogently about the need for **advocacy** at the state level to ensure that their needs are salient to policy makers.

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Report Sponsored By:

