A VOICE THAT MATTERS

The Impact of Family Caregiving in Alabama

Volume II

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The Administration for Community Living

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Alabama Lifespan Respite

An update for public policymakers presented by the Alabama Lifespan Respite Coalition, the Alabama Department of Senior Services, and Alabama Lifespan Respite

Introduction

For more than 761,000 Alabama caregivers, the need for support services and respite continues to grow as more individuals and families choose for their loved ones with disabilities and chronic conditions to remain at home versus receiving institutional care. An extended network of family and friends is not always available to help provide the care, relief, and support that is needed. Thus, respite is a lifeline for the family caregiver. Respite care provides the pause that the single mother needs after taking her child to daycare and rushing back home to care for her aging mother, all before going to work. Respite is the occasional break for the cashier at the pharmacy who is working as much overtime as possible to pay for her disabled child's incontinent supplies that no other funding source will cover. It is for the 75-year-old neighbor who has been up all night keeping her spouse safe due to his wandering, confused, and combative state because he suffers from dementia.

In 2018, Alabama Lifespan Respite ("ALR") provided 45,481 hours of relief or respite care to 1,280 family caregivers at a direct cost of $480,786. Free caregiver education was provided to 1,393 full-time, unpaid caregivers, providers, businesses, and agencies. ALR provided $3,000 in grants to four organizations across the state to enhance respite opportunities for all family caregivers. The combination of family caregiving, respite, and educational training is vital to keep loved ones at home where they want to be and where their family caregivers want them to be.

By 2030, one in five individuals in Alabama will be 65 or older[1]. This population will be living longer but will have more complex and chronic health care needs. While most older Alabamians want to live as independently as they can for as long as possible, this can be difficult for family caregivers, especially with competing obligations. Respite reduces the strain on family caregivers, allowing them to manage their own health care needs as well as the needs of those they care for. As our state ages, planning for the care of older adults and the support services needed for their caregivers is an urgent policy priority.

This paper offers recommendations and provides critical updates to ensure respite, education, assistance, and advocacy are available for Alabamians serving as caregivers. Policymakers will need to address significant challenges and opportunities to elevate our state's current family caregiving approaches. Individuals, families, communities, and the state are strongest when we assist caregivers by providing an enhanced quality of life through resources, education, and tools promoting independence and self-sufficiency. We ask that lawmakers work towards legislative strategies that will enable Alabama to adequately meet the needs of caregivers.

I. Where We Have Been

A considerable portion of respite care is provided voluntarily. However, the larger vision for our state has been the establishment of respite and caregiver supports as a funded service across the lifespan. Advocacy efforts with the Alabama Legislature resulted in Alabama Lifespan Respite receiving state funding beginning in 2006. In 2009 the Alabama Legislature passed HJR 170, establishing Alabama Lifespan Respite "as the lead entity for lifespan respite coordination in the state of Alabama," and designated Alabama Lifespan Respite as the coordinating agency for the Alabama Respite Coalition.

Continuing from those efforts, the Alabama Lifespan Respite Resource Network (Act No. 2012-410) was passed into law in 2012 and codified as Code of Alabama 1975, § 22-5B-4. The Alabama Department of Senior Services (ADSS) applied for and received one of the first federal Lifespan Respite grants in 2009. With support from multiple Lifespan Respite grants from the Administration for Community Living (ACL), ADSS has continued building a comprehensive and coordinated Lifespan Respite system. Projects have been targeted at coordinating outreach, information, and screening for respite services through the Aging and Disability Resource Centers (ADRC) while disseminating information and providing specialized training for family caregivers, providers, and volunteers. The Alabama Lifespan Respite network has been connecting family caregivers across the state with options as early as possible. Alabama Lifespan Respite has also been improving access to respite services and providing a streamlined, coordinated effort with person-centered approaches to meet the needs of family caregivers of children and adults regardless of income, race, ethnicity, or special needs. Past grants have been successful through collaboration among ADSS, the Alabama Lifespan Respite Resource Network™, and the Alabama Respite Coalition. The provision of respite services has been limited in Alabama; however, the awareness and need for respite for family caregivers have increased through the efforts and support provided by federal grants.

A. Our Partners

In 2000, Alabama Lifespan Respite began working with a task force of approximately 45 volunteers from state agencies, non-profit and for-profit organizations that serve people with disabilities, and consumers. At that time, this task force developed an initial strategic plan to identify the respite needs of caregivers and the gaps and barriers they faced accessing services. During the 2009 grant period, ADSS worked in partnership with these organizations to provide a statewide comprehensive and coordinated approach to providing lifespan respite care to all Alabama family caregivers regardless of their disability, illness, age, income, race, ethnicity, special needs, or situation.

In 2012, the members of the Alabama Lifespan Respite Coalition were designated by the Governor of Alabama. The Coalition is comprised of culturally, economically, and geographically diverse members. The Coalition's responsibilities are to:

(1) Build partnerships and coordinate respite care efforts statewide;
(2) Provide public awareness about respite to the citizens of Alabama; and
(3) Identify, coordinate, and develop community/funding resources for respite services.

B. Vision

All caregivers in Alabama will have access to available high-quality respite.

C. Mission

To promote and provide a statewide, comprehensive, and coordinated approach to meet the respite care needs of Alabama family caregivers of individuals with disabilities and chronic conditions regardless of age, income, race, ethnicity, special needs, or situation.
Alabama's Lifespan Respite Resource Network is working to achieve the vision and mission by:

(1) Enhancing respite opportunities for all family caregivers;

(2) Increasing and expanding support services to caregivers utilizing existing and expanded training and educational opportunities; and
(3) Strengthening advocacy and education to public officials and policymakers to encourage implementation of expanded home and community-based services policies to include the caregiver and provide funding for formalized, sustainable respite and support services for caregivers.

Addressing the needs of family caregivers across the lifespan is a continuing and developing endeavor. It is the desire and purpose of this report to share updates and new recommendations that have resulted from the continued work of Alabama Respite and the Coalition. ADSS thanks those individuals and the organizations they represent for their dedicated service and commitment to supporting family caregivers.

D. Where We Are

In Fiscal Year 2019, Alabama Lifespan Respite ("ALR") provided 31,815 hours of relief or respite care to 825 family caregivers at a direct cost of $280,745. Free caregiver education was provided to 1,922 full-time, unpaid caregivers, providers, businesses, and agencies. ALR provided $6,000 in grants to two organizations across the state with developed respite opportunities for all family caregivers. The continued efforts of family caregivers, respite, and educational training are vital to keeping their loved ones at home where they want to be and where their family caregivers want them to be.

ADSS, through Title III-E funding under the National Family Caregiver Support (NFCSP) program, provided 1,299 caregivers a total of 119,323 hours of respite care in Fiscal Year 2018. In Fiscal Year 2019 caregiver supports provided by the NFCSP program through ADSS assisted 8,535 unduplicated caregivers. Of those caregivers, 1,368 received 103,550 hours of respite care. The NFCSP is the primary or only source of caregiver support provided through Area Agencies on Aging (AAAs) in nearly 75 percent of service areas. Results also indicate that in states which had established caregiver programs before the NFCSP, the number of caregivers served increased substantially after implementation of the program (The Lewin Group, 2016).

Alabama Medicaid reports that even with the agency's restricted financing, they covered 25 percent of all Alabama citizens at any given time during 2017. Medicaid certified 216,548 people age 65 years of age or older, blind, or disabled. This included 52 percent of all Alabama children. Aging, visually impaired, and incapacitated beneficiaries represent a modest rate of 31 percent of those who qualify for benefits. Yet the expense of providing support services, which includes respite care, associated with this group accounted for approximately 63 percent of the agency's expenditures. According to Alabama Medicaid's State Plan, this included individuals eligible or deemed eligible for SSI Disability through the Social Security Administration, and other aged, blind, or disabled individuals who meet income, resource, and medical level of care criteria, and who receive services in a certified Long-Term Care facility or receive Medicaid Waiver services in the community. Many of these individuals receive support services and brief respite care relief in a long-term care facility or in the home while enrolled in the Medicaid Waiver program.

Long-term support services provide respite care allowing trained caregivers to attend to a recipient's needs and perform care activities, in either a planned or emergency capacity, providing temporary relief for the primary caregiver to attend to their own needs. These services are primarily provided in a home setting but also occur through adult day care centers and overnight residential facilities (ARCH National Respite Network and Resource Center, 2018).

The Legislature's appropriation of funds used for respite across the lifespan has had a large impact. These funds have increased support services for families while laying the foundation for more extensive partnerships with providers, as well as with medical and business communities. With continued legislative support and combined efforts and partnerships across the state, Alabama Lifespan Respite continues to make progress towards implementing a sustainable system for community-based respite and caregiver support services programs.

II. Public Awareness

A. Website

In April 2019, with assistance from Coalition members, Alabama Lifespan Respite began an inclusive campaign to update its user-friendly, on-line search for respite providers. Members were asked to complete an online survey and/or complete an electronic information form to update for an accurate, comprehensive e-list of respite providers across the state. Caregivers can quickly and efficiently access an on-line database through a state map. A caregiver can narrow their search criteria by choosing in which county respite is needed and by disability and age group to submit a query. Alabama Lifespan Respite neither promotes nor endorses any respite provider over another. This will be an ongoing process.

B. Respite Awareness Day

With assistance and coordination from Coalition members, Alabama Lifespan Respite promotes a "Respite Awareness Day" at the Alabama State House. Educational and informational materials are provided to family caregivers, state legislators, and the public. The availability of funds has allowed the Alabama Lifespan Respite staff to educate family caregivers and state legislators about the role, importance, and utilization of respite services

C. Outreach Events and Activities

Targeted outreach remains a top priority in the state. Outreach efforts are conducted through presentations, conferences, civic groups, newsletters, email blasts, social media, and radio. Funding for respite training vouchers and increased awareness has allowed Alabama Lifespan Respite to educate family caregivers about the role, importance, and utilization of respite. Alabama Lifespan Respite utilizes its website as well as social media platforms, such as Facebook, Instagram, Twitter, and Constant Contact, for wide-scale dissemination of information. Brochures, rack cards, and fact sheets are provided to all Coalition members as well as disseminated across the state.

D. Respite and Caregiver Training

Alabama Lifespan Respite offers training on a variety of topics and has certified staff to train caregivers upon request. A comprehensive list of respite and caregiver training resources is available on Alabama Lifespan Respite's website. Many caregivers feel unprepared to provide care or believe they have inadequate knowledge to deliver proper care. Training has been enhanced to reach special-needs populations. This training includes assistive technology for caregivers and recipients living with age-related disabilities, such as Alzheimer's disease, dementia, arthritis, stroke, Parkinson's disease, low vision, hearing impairment, and more. This training introduces various assistive technology devices designed to reduce the caregiver's stress and the potential for injuries. Assistive technology enhances the quality of life and often increases an individual's self-esteem, in turn promoting more independence and self-sufficiency for both the caregiver and care recipient. The "*Lunch and Learn*" training is intended to increase awareness among the general populace about caregiving, respite, and the full spectrum of Alabama Lifespan Respite's services that are available to caregivers. Since many professional, paid caregivers are required to complete a minimum training standard, this training has been expanded to collaborate with new and existing partners providing support to businesses. This is done by conducting brief educational workshops tailored to employment needs for family members, informal, unlicensed caregivers, and direct care workers of such organizations as home health care, out-patient service centers, or assisted living providers. "*Caregiver Simulations*" offer strategies for coping with troubling behaviors, techniques to offset the impact of stress on the health of caregivers, tools for effectively identifying solutions to specific challenges, problem-solving, and communication skills. This training is designed to create empathy in pre-professionals and current professionals.

Despite progress that has been made since receipt of federal funding, there remain unmet needs for caregiver respite and supports in Alabama. Programs currently available for the purpose of providing caregiver supports are not fully achieving their potential impact because of limited and unstable funding, workforce limitations, and a lack of an automated means to track and improve performance measures. According to Caring.com, in 2017 Alabama ranked among the worst states for providing services and supports to family caregivers. The report evaluated two main categories: the state's score for "Support for Family Caregivers Long-Term Services and Supports" state scorecard, and the availability of highly rated senior care options (such as assisted living communities and in-home care agencies) relative to the state's population of residents aged 65 and older. Alabama's overall rank was 46 out of 50 states and Alabama ranked 50th for caregiver supports. The Journal of Nursing Education and Practice analysis of a caregiver survey reports that many family caregivers in a statewide sample found it difficult to bear the expense of respite without assistance from state and/or nonprofit agencies. The analysis indicates nearly half of those who received respite said the most recent service was insufficient to meet caregiver needs. Moreover, some family caregivers could not find respite services when needed. Waiting for this needed service strains existing caregiver capacity, leading to burnout and significantly increases the use of emergency, acute, and long-term care facilities.

Caregiving has always been hard, no matter how courageously and nobly some family members have embraced it. It is becoming more difficult, demanding, and grueling due to the level of complex medical needs. Dr. Barry Jacobs, PsyD, articulates a startling reality in his book "Emotional Survival Guide for Caregivers" by stating, "There is a strange paradox that exists in our country. At a time in the history of our medical system, health care professionals have knowledge and technologies at their disposal in ways to make them more self-assured than ever in fighting diseases, yet for those embarking on the caregiving journey, family caregivers rarely if ever have been left so stressed, threatened and afflicted." Additionally, the AARP Public

Policy Institute found the supply of family caregiver support is not expected to keep up with the large number of older adults who are living longer and will need more caregiving assistance.

E. What services do caregivers find most helpful?

Based on responses to the 2017 National Survey of Older Americans Act Participants (NSOAAP), 50% of caregivers report that respite services (including adult day care) are the most beneficial to them. To understand the needs of Alabama caregivers, the Alabama Lifespan Respite staff collected data from multiple survey invitations. The data was analyzed and used for program improvements and to suggest areas to develop procedures toward implementing a comprehensive sustainable plan.

These surveys and evaluations are aimed at learning more about the unmet needs of caregivers across the state and supporting the need for legislative policies that will include caregivers, as well as providing funding for formalized sustainable respite and support services. To achieve a comprehensive and quantitative understanding of this problem, individuals who attend conferences, workshops, training, or apply for respite services are invited to participate.

F. Methodology and Results of Surveys

The surveys were conducted by Alabama Lifespan Respite through the online survey site, Survey Monkey. An analysis from September 1, 2018 – February 28, 2019 showed 1,252 total responses resulting in a confidence level of 96% and a confidence interval of plus/minus 3.6%.

Survey respondents are comprised of the following groups:

- Unpaid Family Caregivers (70.67%)
- Paid Caregivers (2.67%)
- Care Recipients (1.78%)
- Service Providers (e.g. Social Worker, Administrator, Case Manager) (23.11%)
- Policymakers (1.78%)

Key takeaways from the collective results are as follows:

- Nearly 71% of caregivers surveyed classified themselves as an "unpaid family caregiver"
- Before receiving respite services, when caregivers were asked if they often felt overwhelmed with daily routines, nearly 81% answered "often" or "every day." When the caregivers were asked the same question after receiving respite services nearly 26% answered "often" or "every day," a decrease of 55%.
- Nearly 89% believe that receiving respite services is vital to their physical, spiritual, and mental health
- When asked, "How important is respite?" on a Caregiver Simulation Pre-Test, nearly 82% of caregivers surveyed answered "somewhat important" or "very important." When asked the same question on a Caregiver Simulation Post-Test, nearly 98% answered, "somewhat important" or "very important," an increase of 16%.
- When caregivers were asked "How much support do you feel comes from the state and community?" nearly 88% answered "none at all" or "some support," compared to only 9% who answered, "enough support."

Based on the initial results, it was clear that family caregivers do not feel supported by the state and their respective communities at large. The respite vouchers, coupled with the training and education provided to caregivers across the state, are paramount to their physical and emotional wellbeing. Although Alabama's poverty for adults aged 65 and older is only 10%, many caregivers are struggling to find affordable care. This is due in part to limited and unstable funding, along with eligibility criteria and a general lack of awareness. Alabama continues to see the need for respite services increase, as evidenced by the multitude of individuals currently on waiting lists.

To evaluate the needs of Alabama caregivers, AARP conducted a caregiving survey in 2019. One thousand caregivers across the state were surveyed to determine the need for legislative policies that would include caregivers. Most respondents to the Alabama survey who received respite praised its benefits and indicated they would feel stressed if respite was unavailable. Unfortunately, nearly half felt the most recent respite was insufficient to meet their needs, straining their caregiving capacity. Although AARP worked to introduce new legislation supporting family caregivers during the 2019 legislative session, the legislation failed to get out of committee. Thus, Alabama's ranking among the worst states for providing services and supports remains unchanged.

In talking with Alabama caregivers, they were asked, "If you could have one service to assist with the daily tasks of providing care, what would you ask for?" Below are examples of answers:

- Qualified professional help to assist loved one with daily tasks (bathing, skilled medical care, hygiene, etc.) to prevent family burnout;
- A case manager to help coordinate a plan of action;
- More hours of help;
- Relief during the day to recharge and perform other tasks; and
- Easier transportation and more group homes.

The most recent statistics regarding Alabama's aging and disabled populations show a high number of family caregivers.

- According to the Social Security Administration (SSA), in 2017 approximately 226,922 adults and 99,545 children living in Alabama received some form of social security disability benefits. It is estimated that Alabama's total was $3,680,000.
- AARP estimates the prevalence of disability in Alabama is 14.4%, which includes 421,000 adults over the age of 18. This would rank Alabama number 5 in the nation for this category.
- Data provided by the Alabama Department of Rehabilitation in 2017 showed there were 7,033 families served by the Early Intervention Program (0 – age 3). This includes both children with developmental delays and children with diagnoses that increase the risk for developmental delays (e.g. cerebral palsy, spinal bifida, etc.).
- In 2017 the State Department of Education served 90,319 Special Education children with qualifying disabilities.
- In 2018 the National Alzheimer's Report showed a projected number of 92,000 Alabamians over the age of 65 with Alzheimer's or other dementia-related diseases. This

report estimated 304,000 caregivers with 346 million unpaid hours of care at a value of $4,367,000.

- According to the 2018 Older Americans Profile Tables, Alabama's population of 65 and older for 2017 was 803,771, a 29.4% increase from 2000 to 2017.
- In 2017 the Alabama Department of Mental Health served 106,740 individuals with mental illness and 5,744 individuals with intellectual disabilities.

Chronic health conditions not only affect the quality of life but also present a financial burden for state government and caregivers. Statistics show that regular supports for unpaid caregivers reduce depression and anxiety and promote a sense of well-being, thus making it possible for caregivers to maintain their vital roles. Without adequate caregiver supports, family caregivers struggle to care for their loved ones at home safely, often leading to premature institutional placement. Alabama would do well to create solutions that would ensure accessibility, availability, and quality support services for unpaid family caregivers. The Alabama Lifespan Respite Network is critical to Alabama's provision of support services for caregivers. The services reflect the needs of caregivers in their communities and provide an enhanced quality of life to those for whom they provide care.

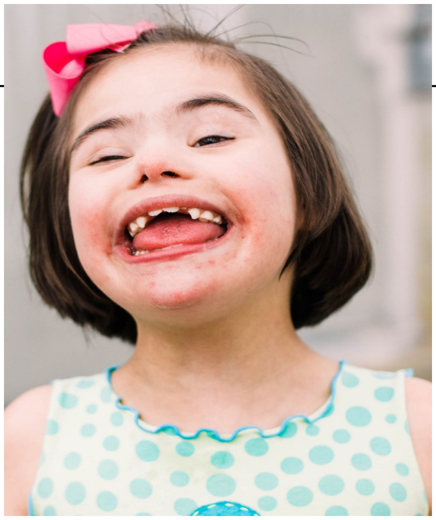
ADSS and Alabama Lifespan Respite urge policymakers to:

- maintain the Alabama Lifespan Respite resource commitment to enhance and expand existing respite and support services to family caregivers of children and adults; and
- develop a policy framework that will expand and strengthen Alabama's current lifespan respite care initiatives, to ensure continued services reflect and meet the unique needs of all family caregivers.

III. The Voices and Faces of Respite

This section captures the importance of Alabama Lifespan Respite and why it is so vital to ensure that respite and support services are available for all family caregivers. The voices and faces of respite share the stories of family caregivers who have benefited from taking a much-needed break from caring for a loved one.

Our family brought Maya home from Bulgaria in 2013. While we knew about her primary diagnosis of Down Syndrome and the delays that would bring, we didn't understand the practical challenges that her day-to-day care would bring. The changes her care brought to our family were significant. We have three other children, and it really began to impact their daily lives in ways that they could not understand, and honestly, it wasn't fair. As Maya's care became more complex, she received an additional diagnosis of autism and she was requiring constant careful supervision. It was keeping us from doing activities together as a family, and it was keeping my husband and I from spending time together that the two of us occasionally needed. I discovered Lifespan Respite at the Alabama Disability Conference in Montgomery. The representative took time to talk with me and explain how the system worked, and I got home and immediately applied. We were approved, received the respite voucher, and then began receiving funds to cover a desperately needed respite worker. The changes that this brought have been significant. We've been able to take our 'typical' children and do things that they enjoy again without the constant responsibility and focus on Maya's care, and my husband and I are able to take a few hours a month to spend time together. There's not a thing in the world we would give for Maya's presence in our family. She's a beautiful little girl with lots of spunk and love. But our family, like so many others, benefits more than we can describe from Lifespan Respite. Without their help and provision, it would be extremely difficult to maintain the balance that every family with an extra-special member needs.



What Respite Means to Me

I recently lost my wife due to complications resulting from frontotemporal degeneration (FTD). She had the language variant, primary progressive aphasia (PPA) which took away her language abilities. For the past five years, I have been her primary care partner. Up until the last ten days of her life, she lived at home with me. As my wife's disease progressed, I learned that caregiver stress can lead to multiple problems. I often told people that my wife's brain disorder was a dual threat disease, meaning that I, as her care partner, needed to remain vigilant about caring for myself. With 70% of caregivers either succumbing to stress related illness or dying prior to their loved one, I was not about to become another statistic. For that reason, I sought respite whenever I could. Most recently, I was able to utilize an emergency respite grant to help manage the private pay nursing home expenses in the facility where my wife passed. Her placement had been the result of a temporary displacement from our home due to some needed damage repair to our house. Her death was not expected. The grant, most assuredly, helped ease my emotional pain and mitigate my financial burden during a very stressful time. I am grateful that I discovered Alabama Lifespan Respite. Their respite care grants have been a godsend for me, helping me to manage the caregiver load while maintaining my physical and emotional health. After all, had I not been able to find respite time away from the daily stress of care giving, I would not have been able to provide quality care for my wife during the full progression of her disease. Who knows? I could have become just another statistic, and, then, who would have taken care of her?

This is Michelle from Phenix City. We are a family of five. Three of which happen to be triplet boys. All three of the boys have been diagnosed with autism spectrum disorder, as well as other manifestations that accompany ASD. Our boys were born prematurely; 32 weeks. After the boys were brought home, we didn't take them out in public. We feared that they might catch who knows what from the general public. Not only that but, all the extra stuff you needed to pack just to leave the house! It would take me longer to pack & load them up in the car, than it actually took me to run the errand. So, basically, I became a hermit. The schedule with multiples is an absolutely wonderful and beautiful experience...some might say. Well, it absolutely unequivocally is NOT! Lack of sleep, hygiene, depression, friendships, eating, spouse time and every other activity you had prior to your miracles coming home, ceases to make it in your calendar. I didn't get the opportunity to enjoy them and our family as much as I should have. I have often referred to that time as my survival period. There was no time for anything else, let alone any outside interests that I might have had prior to the babies. From the day the boys were born until they were five years old, I had not had any time away from them. No time to take care of myself. I haven't been to my dentist since 2011! I was religious about my six months appointments. Now, I keep putting it on my to do list, but somehow it inadvertently gets placed at the bottom. And that goes for really anything that I used to.

Respite for individuals that are caregivers is even more so important than the dependent, at times. Because if they cannot take care of themselves mind and body, how can they be effective for their loved ones. Oh, how I used to hear that from everyone outside of my home. Everyone who says that I believe, truly means it, but getting someone to actually step forward and volunteer; another story entirely. However, along came some beautiful ladies whose lives mirrored mine with special needs children. As we exchanged stories and experiences, I was introduced to Alabama Respite. I have learned so much more and my life, as well as my family's lives, have grown richer for the experiences. Really, it doesn't matter what you do with your respite time, reading a book undisturbed, taking a walk, connecting with friends, or just fulfilling your personal appointments. Life still has to happen. Connections with the outside world and/or yourself, is just as important to your mental and physical well-being.

Dear Sirs,

My name is Yolanda Lewis. My mother-in-law (Claudette Lewis) is seriously ill and has a long history of mental health issues such as Schizophrenia and more recently Dementia. Additionally, Claudette has Type-1 Diabetes, Congestive Heart Failure, kidney failure and has a pacemaker. I have become the primary caregiver for Claudette because my sister-in-law, who was my husband's only sibling died a year ago. Claudette lived with her daughter Angela for nearly a decade since the passing of her husband (Andrew Lewis Jr.) in 2010. Moreover, my husband Andrew Lewis III is a 22-year firefighter and is away at work for half of each week. This leaves the majority of Claudette's care on me, and there are no other willing family members, friends, neighbors, or anyone else concerned about or willing to assist with my mother-in-law's health care needs.

Much of the time, Claudette is depressed, confused, and disoriented. It is for this reason that she is not responsible for any part of her daily care. She has severe edema in her feet, ankles, and legs, and needs help with meals, bathing, dressing, and medications. She is not clear-thinking enough to check her blood sugars, blood pressure, and she must be given insulin injections. I don't think she even knows which medication she takes daily.

Also, I have a small child who will begin 1st grade this upcoming school year. So, our schedule is quite intense and demanding. Some days it is difficult for me as I negotiate severe chronic head, neck, and back pain, not to mention, a surgically altered/fused cervical spine.

So, I must honestly say that the Respite Care Program is priceless and has offered me and my entire family a lifeline, and a sense of hope by way of allowing us to have providers come in, and help with my mother-in-law's bathing, meals, cleaning her room, doing her laundry, and providing meals for her. Also, I notice that she looks forward to her scheduled time when her care provider(s) are in our home. Furthermore, the assistance that we received allows me to spend time outside with my 6-year-old, help our daughter with homework, and allows her to have time away and play dates with children her age.

We thank you for your support and want your organization to know that what you do is highly valued and appreciated by our family.

Sincerely,

Yolanda Lewis

Yolanda Lewis

IV. Where Are We Heading?

According to estimates from the National Alliance for Caregiving, during the past year, 65.7 million Americans, or 29% of the U.S. adult population involving 31% of all U.S. households, serve as family caregivers for a relative who is ill or has disabilities. According to the 2017 U.S. Census, there were 51 million people aged 65 and older, which was 15.2% of the U.S. population. 833,000 people aged 65 and older live in Alabama. The U.S. Census Bureau estimates Alabama's resident population to be 4,874,243 by 2030 with those 65 and older estimated to increase by 50% through the year 2040. While we have made significant progress in increasing the availability of respite services, the number of people with disabilities and special needs in all populations continues to grow. As a state, we still have a long way to go to address the needs of all family caregivers across the lifespan. Advancing Alabama's lifespan respite care initiatives into a formalized sustainable respite and support services system for caregivers is a developing and extensive process – one that requires consistent evaluating, examining, and modifying to meet the ongoing needs and emerging trends of caregivers. Approaching the next phase, Alabama will propose new solutions to add to a plan of action that will guide us into the future.

A. Older Alabamians

According to the U.S. Census Bureau, the estimates are that one in five Alabama residents will be over the age of 65 by 2030, and by 2035, seniors will outnumber children (younger than 18). This population is living longer with more complex and chronic health conditions. Obesity, the leading cause of preventable years lost and contributing to more chronic illnesses such as heart disease, diabetes, cancer, and hypertension, rose at a rate of 2% in Alabama during 2018 as compared to 2017 data. It is important to develop an action plan now to address the needs of this growing population that will include their caregivers.

The Lewin Group provided a written summary of the comprehensive evaluation conducted for the federally funded NFCSP. The results from the 2016 report state, "The impacts of caregiving indicate a critical need to support informal caregivers in their roles so the caregiving needs and preferences of a growing older adult population can be effectively met." The program, which is operated through Alabama's 13 AAAs, is creative, utilizing targeted methods and partners to reach vulnerable caregiver populations. One such critical partnership is with the Alabama Lifespan Respite team.

Recently, the United Health Foundation created its *2019 America's Health Rankings^{R} Senior Report.* This report documents a comprehensive analysis of the health of seniors across the nation and each state. Alabama ranked 44 out of 50 on a combined 34 measures. Among 23 of the measures, Alabama ranked worse than the median. The health issues having the largest impact on the senior population are: dedicated health care providers, hospital deaths, falls, early death, preventable hospitalizations, home healthcare workers, and high health status, a generic term referring to the health (good or poor) of a person, group, or population in a particular area, especially when compared to other areas or with national data.

The state of California provides an interesting comparison. In January 2019, Governor Newsom signed an Executive Order calling for a cabinet-level workgroup to advise in the development of a "Master Plan for Aging." California's aging population is expected to almost double over the next twenty years from 5.4 million to 10.3 million. Just as with other states, their aging population is expected to become a larger share of the total population by 2030. Although Alabama may not be comparable in size, population, or projected growth to California, Alabama legislators should be knowledgeable about preparing for the substantial growth of its aging population. The key principles outlined in California's aging plan are focused on Economic Security, Equity, Intergenerational, Comprehensive, Intersectional, and Person-Centered Long-Term Services and Supports.

With the rapid increases in the aging population and rising rates of senior poverty, prioritizing health care and long-term services and supports for aging Alabamians and their family caregivers should be at the center of developing or redesigning care models. Because aging impacts every generation, care models should include family caregivers. Acknowledging their value will not only improve the care experience but will also improve quality care and improved outcomes for this population. Care models are needed to ensure access to health and support services that will reach the most vulnerable. This will help narrow gaps of unmet needs.

B. Workforce Limitations

The baby boomer generation is aging and the need for help with this demographic is growing fast. This will increase the need for home health aides and/or homemaker job positions. A 2018 "Cost of Care Survey" conducted by Genworth Financial, calculated the median hourly rate for a licensed home health aide or homemaker in Alabama is $17.00 and the median daily rate for adult day care is $35. Although the salary and costs for these services will most likely increase over time due to the demand from aging baby boomers and the growing elderly population, the cost would still be far less than full time assisted living or nursing home care at a rate of $3,271 per month for assisted living and $6,279 for nursing home care in a semi-private room. As Alabama moves towards a managed care system, the state would do well to have an enhanced data infrastructure with which to address the demographic challenges on the horizon of developing an adequate workforce. Using data to leverage managed care contracts to establish expectations, or in some cases requirements, for their managed care plans' role in this effort would be beneficial. The number of potential family caregivers (ages 45–64) for every person in the high-risk years (ages 80 and older)—which AARP calls the caregiver support ratio—is declining. Nationally, the ratio of caregivers will drop drastically from 7.2 which was reported in 2010 to 2.9 by 2050. All states will be impacted, but some states will be harder hit than others.

C. Working Caregivers

Caregiving comes with financial obligations. AARP reported in 2016 that family caregivers spent on average just under $7,000 per year, or 20% of their income, on caregiving expenses. An estimated 43.5 million adults provide unpaid care of some sort to an adult or needy child and, of the 43.5 million, 34.2 million care for an adult aged 50 or older. Nearly half of caregivers care for those 75 and older. The average caregiver spends 24.4 hours a week providing direct care, which is the equivalent of a part-time job. Almost 70% of employed caregivers report having to rearrange their work schedule, decrease their hours, or take unpaid leave to fulfill their caregiving responsibilities. Other statistics from the report indicate 61% of caregivers experience at least one change in their employment due to caregiving. These changes ranged from cutting back work hours to taking a leave of absence after receiving a warning regarding performance/attendance, among others. In general, Alabama businesses incur high costs in terms of decreased productivity by stressed working caregivers. A study by MetLife estimates the financial loss to employers to be between $17.1 and $33.6 billion per year. This includes replacement costs for employees who quit because of overwhelming caregiving responsibilities, absenteeism, and workday interruptions.

Caregiving can deal a major career blow. The Family Caregiver Alliance states that 1 in 6 Americans working full-time or part-time report assisting with the care of an older or disabled family member, relative, or friend. These individuals indicate that caregiving has a significant impact on their work. 22% of working caregivers are middle-aged and 13% are between the ages of 18 and 29. On average, caregivers who are employed work 34.7 hours per week. According to the AARP Public Policy Institute, 49% arrive at their place of work late/leave early/take time off, while 15% take a leave of absence, 14% reduce their hours/take a demotion, 7% receive a warning about performance/attendance, 5% turn down a promotion, 4% choose early retirement, 3% lose job benefits, and 6% give up working entirely. Caregivers suffer loss of wages, health insurance, and other job benefits, retirement savings or investment, and Social Security benefits – losses that carry serious consequences for working caregivers and their future. [National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S.] Two out of three caregivers support additional policy proposals preventing workplace discrimination against employees with caregiving responsibilities.

D. Caregivers of Children with Special Needs

Caring for children with disabilities presents socioeconomic and psychological challenges for the whole family. According to the study “Caregiving in the U.S.,” there are an estimated 16.8 million unpaid caregivers who provide care for a child under the age of 18 who has a medical, behavioral, or other disability. Examples include conditions such as autism, Down syndrome, cerebral palsy, developmental delays, etc. Many of these caregivers are caring for two or more individuals. Physical strain is more common among caregivers of children with special needs (64%) than it is among those caring for adults (55%). Most caregivers who care for children with special needs report that the responsibilities have affected their social and financial well-being. Sixty percent say it puts a strain on their relationships and time spent with other family members. Three out of four report making changes to their work situation, and their caregiving responsivities have had severe impacts on their employment situation by causing them to cut hours, take a less demanding job, leave work entirely, or lose benefits. They are also more likely to have taken a leave of absence.

The Alabama Medicaid FACTS Sheet reports approximately 20% of children have special health care needs and 44% of those are covered by public insurance. According to the Cornell University *2017 Alabama Disability Status Report*, 2,400 of the 286,700 children ages 0 to 4 in Alabama reported as having one or more disabilities; 38,900 of the 677,900 individuals ages 5 to 15 in Alabama reported one or more disabilities. Alabama Medicaid covers over 658,242 low-income children. Children are not the cost driver of Medicaid spending, but they account for approximately 19% of spending. The Children’s Hospital Association reports 64.5% of children enrolled in Medicaid live in a family where at least one caregiver works full-time. These caregivers need to have access to reliable information. They are more likely to use the internet to find supportive information needed for the special health care needs of their children. Many caregivers of this population state they would prefer a caregiver tax credit. Many would like to receive a voucher program that would pay them minimum wage for some of their time spent caregiving or provide vouchers for respite services.

E. Grandparents Caring for Grandchildren

Just when grandparents think the next stage in life will be retirement and freedom from family responsibilities, another round of parenting grandchildren may present itself, and expectations are that the number of grandparents parenting grandchildren will grow. The latest recorded Alabama data showed in 2015, approximately 62,047 grandparents had the primary responsibility of caring for their grandchildren. Many grandparents have looked forward to spending their retirement years cutting back on jobs and stress, finally having the time to pursue interests, do volunteer work, or even start a new business. However, the trend of grandparent caregiving is a result of many social and economic issues such as poverty, the opioid epidemic, substance abuse, the death of a parent, and extended military deployment. According to the Administration for Community Living (ACL) 2018 Profile of Older Americans, approximately 1.1 million grandparents aged 60 and over were responsible for the basic needs of one or more grandchild under age 18 living with them in 2017. Grandparent caregivers must make decisions that include delaying retirement, working with different generations, dealing with school systems, navigating the court systems, and finding appropriate mental health services. They often do not know where to turn for help, which makes a demanding situation even more stressful.

In 2018 Congress passed the Supporting Grandparents Raising Grandchildren Act with expectations to help 2.6 million children being raised by grandparents or another family member. These numbers are expected to continue to grow with the national opioid epidemic.

There are role conflicts between the natural role of grandparent and the new role of “parent.” Financially, some grandparents are assuming more debt and barely surviving on their Social Security checks. Grandparents must take on the financial responsibility of school clothes, extra-curricular activities, additional groceries, health insurance, and doctor bills. Grandparents who are retired and living on a fixed income often need assistance to deal with the additional expenses of taking care of children during their retirement years.

F. Aging Parents of Children with Mental Disabilities

Many parents who have cared for their children with mental disabilities are aging and facing challenges with their own health. They find it challenging to perform some of their own traditional daily living responsibilities such as feeding, bathing, toileting, and assisting with other activities of daily living. They have the added stress of what will happen to their loved ones in the event of their death. Many of these caregivers have not utilized any outside assistance. Many times, siblings of the care recipient are occupied with their own lives which can result in a lack of support and care for their disabled siblings. Some of the challenges experienced by these caregivers are:

- The long waiting list for community care;
- Inexperienced staff who do not stay in jobs for long;
- Fear of losing services due to future policy or funding issues;
- Lack of day programs; and

- Respite.

Many of Alabama's long-term services and supports (LTSS) through the Alabama Medicaid Agency focuses on "person-centered planning" with the care recipient in mind and not the caregiver or the family holistically. There are limited public dollars and these dollars are directed towards the care recipient. In the rural areas of the state, there are very few support services so many caregivers must function alone with virtually no support. To demonstrate the changes that have occurred in Alabama's LTSS in recent years, an LTSS study for Intellectual and Developmental Disabilities (IDD) conducted through the University of Minnesota entitled the Residential Information System Project (RISP), estimated the number of Alabamians waiting for Medicaid Waivers from 2013-2016 living in the home of a family member increased from 49% to 59%. The number of those waiting was estimated to be 3,324 with a total of 5,580 Waiver recipients. In 2015, 805,615 Alabamians were identified as having a "self-care" disability. In 2018, ADSS served a total of 10,607 Home and Community Based Waiver recipients and 270,271 hours of respite care were provided.

G. Caregivers of Younger Adults

According to the AARP 2015 Research Report: Caregiving in the U.S., it has been estimated that at least 5.6 million adults in the U.S. have provided unpaid care to an adult family member or friend who is 18 to 49 years of age in any given year. 84% of these caregivers report that the recipient of their care does not live alone, indicating 50% live with the caregiver. Caregivers of younger adults say that 43% of those cared for had a short-term physical condition, 36% had an emotional or mental health problem, and 32% have long term physical conditions. 37% have more than one problem or illness.

On average these caregivers spend approximately 26.9 hours per week providing care to their loved one – about the same number of hours as a part-time job. 27% provide more than 40 hours a week. Emotional stress is more common among these caregivers. Most of these caregivers report they need more help or information. Caregivers of younger adults are less likely to have conversations with health care providers about their care recipient. These caregivers would like to advocate for their names to be required on the care recipient's medical records, to see income tax credits, paid leave of absence from work, and a ban on workplace discrimination against employees who have caregiving responsibilities.

H. Caregivers of Individuals with Mental Health Issues

The National Alliance on Mental Health reports the most common mental illness diagnoses caregivers face today include:

- ADHD;
- Anxiety Disorders;
- Bipolar Disorder;
- Borderline Personality Disorder;
- Depression;
- Dissociative Disorders;
- Eating Disorders;

- Obsessive-Compulsive Disorder;
- Posttraumatic Stress Disorder;
- Schizoaffective Disorder; and
- Schizophrenia.

Last year, a report from the National Alliance for Caregiving detailed the financial impact mental health conditions have on caregivers in *On Pins & Needles: Caregivers of Adults with Mental Illness*. Nearly 65% of the 1,601 respondents caring for adults with mental illness reported that their care recipients depended completely or significantly on them for financial support. This compared with 49% of all caregivers. Research suggests caregivers of this population often experience a higher burden of care and higher stress levels than traditional family caregivers. As indicated in several reports, the financial effects included going without "essentials" such as food or heating and being dependent on others to survive. Caregivers reported that these effects had significant emotional impacts on their own mental health, including feelings of worthlessness or feeling guilty about their loved ones going without something they need. On average, these caregivers provide 32 hours of care per week. Among significant barriers, these caregivers report having difficulty finding day treatment programs or peer support and difficulty navigating the mental health care system and interacting with professional providers. The top advocacy issues for these caregivers are policy support to facilitate care access and navigation of the mental health care system and the availability of mental health insurance coverage to have mental health conditions treated similarly to other medical health conditions. As all caregivers express, these caregivers would like to be a part of the mental health team and they express the need for education on mental health issues and resources for assistance.

I. Dementia Caregivers

The Alzheimer's Association, in its publication of Alzheimer's Disease Facts and Figures for Alabama, estimates that in 2020 there will be 96,000 individuals with Alzheimer's or dementia-related diseases. In 2025 it is estimated there will be 110,000 people aged 65 and older with Alzheimer's, an increase of 23.6%. Medicaid has estimated that the cost for those 65 and older living with Alzheimer's or dementia in 2018 was $839 per person. By 2025 the estimated cost will be $1,107 per person. The impact of Alzheimer's and dementia-related diseases on patients, families, and caregivers is a growing public health concern. Studies have found that caregivers of individuals with Alzheimer's and dementia-related diagnoses have higher levels of burden than other caregivers. These caregivers must deal with emotional, psychological, and physical health issues, as well as with social isolation and financial hardship.

According to the National Conference of State Legislatures, Medicaid payments totaled over $46.5 billion in 2018 for Americans 65 and older living with Alzheimer's or other dementia-related diseases. 83% of the help provided to older adults comes from unpaid caregivers. Over half of these caregivers for a loved one with Alzheimer's or another dementia. In 2017, it was estimated that 18.4 billion hours of unpaid care provided by the family would be valued at $232.1 billion. Most of these caregivers are spouses.

J. Caregivers for Veterans

According to the July 1, 2018 U.S. Census Bureau Quick Facts for Alabama, of the state's estimated 4,887,871 population, 341,642 are veterans. Caregivers for veterans are usually parents or spouses of young or older veterans. Many young veterans come home with serious physical injuries and Post-Traumatic Stress Disorder (PTSD). The responsibilities of the caregiver can be overwhelming. Today's medical systems allow more veterans to live longer lives but often with disabilities and psychiatric issues. The typical caregiver of a veteran whose condition is service-related is a woman who is caring for her husband or partner. This is different than the national description of family caregivers, as 65% are women and only 6% provide care to their spouse or partner.

Veteran caregivers are more than three times as likely as family caregivers, in general, to live in the same home as the person they provide care for. The veteran care recipient tends to be much younger than others receiving care nationally, with 41% of caregivers saying the veteran is between the ages of 18 and 54. At least two-thirds of caregivers of veterans say some of their top challenges are:

- Not knowing what to expect medically with the veteran’s condition;
- Not being aware of Veterans Affairs (VA) services;
- Not knowing how to address PTSD or other mental health issues; and
- Difficulty maneuvering through bureaucracies for assistance.

Millennial Caregivers

The millennial generation comprises those born between 1980 and 2000 and is sometimes thought to be self-absorbed and lacking responsibility. Yet, according to the AARP Public Policy institute, one in four family caregivers is a millennial. Their caregiving responsibilities are much like those of other generations in that on average, they provide more than 20 hours a week in caregiving responsibilities. One in three of these caregivers supports someone with mental health or emotional problems. Three out of four millennial family caregivers are employed. Fifty-three percent work full-time, and one in three earns less than $30,000 annually. These caregivers have different experiences and challenges in their caregiving roles. Approximately 43% of millennial caregivers provide care to parents or in-laws and about one in five takes care of a grandparent. More than half are alone in their caregiving duties. Previous generations of caregivers were primarily women, but millennials are splitting caregiving responsibilities evenly by gender. Approximately 33% of millennial caregivers care for someone with an emotional or mental health issue. This is very different from non-millennial family caregivers (18%). Caring for someone with mental health problems is different from caring for someone with physical or functional impairments. Many of these young adults put their lives on hold to care for a family member. For many, this caregiving is like having a second, part-time job. Caregiving can be a lonely undertaking for anyone, but millennial caregivers often do not have the free time or flexibility their peers must establish meaningful relationships. Navigating government services and health care systems, care coordination, and expenses presents major challenges for this group of family caregivers who are very young to have to experience these roles in their lives. Many millennials have student loans and are just getting started as adults and these financial strains are an added stress. According to the AARP Public Policy Institute’s May 2018 article, “Millennials: The Emerging Generation of Family Caregivers,” working millennials are often not recognized and supported in the workforce and they often don’t know how to explain their situations to their employers. Millennial family caregiving challenges are often less understood by their superiors, managers, and employers than challenges associated with childcare. The article goes on to state, “Millennial family caregivers more often received warnings about performance or attendance, turned down promotions, were fired from a job, and/or stopped working entirely.”

V. Impact of Investing

Alabama’s family caregivers provide approximately 80% of all LTSS for their loved ones. And increased demand for caregiver supports in the future cannot be understated when looking at the 65 and older population, which is projected to increase by 50% through 2040. The most cited issues facing Alabama family caregivers are a financial burden, need for respite, and concerns about the caregiving workforce.

Alabama Lifespan Respite is among those programs that directly support caregivers of individuals across the lifespan. This is a system of accessible, community-based respite care services for family caregivers of children and adults of all ages with special needs. Alabama Lifespan Respite was designed to reduce duplication of effort and assist in the development of respite care infrastructures in Alabama as well as at local levels. The purpose of the information being provided is not only to increase public policy awareness of caregivers’ issues, but also to propose solutions creating a sustainable plan for community-based respite and caregiver services programs.

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Caregiver Task Force Members

As Alabama moves towards a managed care system, there is a strong financial incentive to consider strategies, plans, and programs to support and serve the family caregiver. Institutional care is very costly to the General Fund budget. Per the 2018 AARP Public Policy Institute Alabama’s State Profile, Medicaid LTSS spending for older people and adults with physical disabilities (total federal + state) was $952 million on nursing facility spending, or $196 per person. Therefore, supporting caregivers is cost-effective in the long-term. It is recommended that Alabama customize person-centered support strategies for diverse populations and the level of needs for family caregivers.

Creating solutions to support individuals remaining independent at home and their caregivers is the most effective and efficient method to provide real change to LTSS. Increased awareness of respite and the needs of families across the lifespan, through targeted outreach to medical, educational, business, faith, and civic communities is vital. Health care providers, educators, faith leaders, businesses, and employers interact with families every day. The toll caregiving takes on a family caregiver and its impact on their health, the health of the loved one they are caring for, the ability to work, and/or engaging in other important activities affect all aspects of Alabama. Adequate support services for caregivers must be addressed as a priority for long-term care systems change.

VI. New recommendations for state policymakers to consider in supporting family caregivers:

A. Family Caregivers Act

Lawmakers are encouraged to enact the Family Caregivers Act, to recognize the critical role of family caregivers. The Family Caregivers Act bill features three important provisions:

1. Identify: The name of the family caregiver is recorded when a loved one is admitted into a hospital.
2. Inform: The caregiver is notified if their loved one is to be discharged to another facility or back home; and
3. Instruct: The facility must provide an explanation and live instruction of the medical tasks – such as medication management, injections, wound care, and transfers – that the family caregiver will perform at home.

B. Development of policies and programs for a state-subsidized respite care program that includes:

1. Minimum standards for workers providing respite care;
2. An educational or certificate training program for respite care workers;
3. Enhanced training in-person and online;
4. Supervision training to develop advanced roles, allowing direct care workers to advance their careers and offer a higher level of support;
5. State-level funding to recruit and retain a direct care workforce;
6. Increased compensation for direct care workers, with benefit and financial safeguards; and
7. Establishment of a matching service registry that connects family caregivers and direct care workers within the state.

C. Increase Funding for Support Services such as Home Teleconnections

With limited providers available in the rural regions of the state, teleconnections caregiver support services would be a means of integrating cost-effective health care and social supports for family caregivers, if broadband service is available. Family members would have access to learning sessions with clinicians on a variety of topics and communication tools. Health sessions with clinicians and educators would improve the management of such chronic conditions as diabetes. Functional decline and mobility challenges could be more readily assessed using videoconferencing. Support sessions could be held over several weeks to provide a caregiver with the knowledge and skills necessary to manage a loved one's dementia.

D. A Standardized Alabama Caregiver Survey

Build a robust data collection infrastructure to produce new research, analyze family caregivers' needs and direct care workforce on the state and local levels, determine the number of individuals with long-term chronic mental/physical health diagnoses such as dementia-related diagnoses, and the number of family caregivers. This would assist policymakers with future planning and advocacy efforts for the provision of adequate services and supports. The comprehensive monitoring of caregiver outcomes would track and analyze:

- Caregivers' experiences, program satisfaction, and the overall impact of services;
- Potential cost savings due to delayed or avoided institutional placements;
- Reductions in abuse, neglect, or exploitation of dependent persons;
- Care recipients' Activities of Daily Living/Inactivities of Daily Living functioning;
- Potential savings to Medicare/Medicaid;
- Whether respite alone, or in combination with other support services, can improve employee productivity of caregivers (e.g., reduced absenteeism, sustained labor force);
- Proximal outcomes (that are immediately observable);
- Distal outcomes (that emerge over time);
- Costs that could reasonably be expected to occur in the absence of respite;
- Costs that are borne by different parties associated with the provision of respite (in-home vs. out-of-home), different types of respite, and different types of care receivers; and
- Outcomes for both respite-receiving and non-respite-receiving caregivers.

E. Tax benefits for Family Caregivers

Enact a family caregiver tax credit bill that would provide refundable tax credits for certain expenses incurred by a family caregiver for the care and support of a qualifying family member. This would defray long-term care costs and compensate for expenses family and informal caregivers incur.

1. Proposed:

Eligible expenditures for the family caregiver should include:

- Improvement or alteration to the family caregiver's primary residence to enable the loved one being cared for to remain mobile, safe, and independent in her/his home and community;
- The purchase or lease of adaptive devices by the family caregiver, as needed, to assist the loved one in one or more Activities of Daily Living; and
- Costs for equipment or services that help in the care of a loved one, such as hiring a home care aide, costs associated with respite or adult daycare, personal care attendant costs, and health care equipment and technology costs associated with caregiving.

The loved one receiving care must meet the following three conditions:

- Be age 18 or over;
- Require assistance with at least one ADL, as certified by a licensed health care practitioner; and
- Be a dependent, spouse, parent, or other relation by blood or marriage to the family caregiver.

To be eligible for the tax credit, the family caregiver claiming the credit must have a federal adjusted gross income of less than $75,000 for an individual, and less than $150,000 for a couple. The amount of the credit is equal to 100% of the eligible expenses incurred by the taxpayer during the taxable year, with a maximum allowable credit of $1,500. General home care should not be permissible, but options such as home care nurses, aides, or adult day care/adult day health should be included.

2. Benefits:

- Reducing costs while being able to support a loved one
  "The average caregiver spends around $5,500 a year on caregiving expenses such as food, drinks, clothing, gas, and other out-of-pocket costs that may prove burdensome over the long run." (Seniorliving.org https://www.seniorliving.org/investing/caregiver-tax-credits)
- Assistance – relieving the burden of state and local taxes for those caring for a disabled or senior family member
- Financial assistance to those caregivers who are unable to provide full-time care and must hire in-home workers

F. Expansion of Home and Community Based Services

The expansion should include no waiting lists for consumer-directed care. The 2018 findings from the Westat report suggest that National Family Caregiver Support Program (NFCSP) could be more integrated with HCBS providers.

These recommendations would address various challenges faced by caregivers with legislative support. Support services for caregivers ultimately reduce the state's funding of unnecessary hospitalization and reduce costs associated with Medicaid funded long-term care in nursing homes and intermediate care facilities. Respite and support services across the lifespan yield positive outcomes. They make family caregivers better at caregiving, sustain marriages, reduce abuse and neglect, lower levels of stress, improve health, reduce hospitalizations for both the caregiver and care recipient, and improve overall wellbeing.

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