

**Caring for Caregivers: How Pennsylvania Can Support Older Adult Family Caregiver  
Mental Health**

by

**Kelsey Grace Lachow**

BA, University of Pittsburgh, 2022

Submitted to the Graduate Faculty of the  
Department of Health Policy and Management  
School of Public Health in partial fulfillment  
of the requirements for the degree of  
Master of Public Health

University of Pittsburgh

2023

UNIVERSITY OF PITTSBURGH  
SCHOOL OF PUBLIC HEALTH

This essay is submitted

by

**Kelsey Grace Lachow**

on

April 28, 2023

and approved by

**Essay Advisor:** Meredith Hughes, JD, MPH, Assistant Professor, Health Policy and Management, School of Public Health, University of Pittsburgh

Essay Reader: Stephen Albert, Ph.D., MS, Professor, Behavioral and Community Health Sciences, School of Public Health, University of Pittsburgh

Copyright © by Kelsey Grace Lachow

2023

# **Caring for Caregivers: How Pennsylvania Can Support Older Adult Family Caregiver Mental Health**

Kelsey Lachow, MPH

University of Pittsburgh, 2023

## **Abstract**

Family caregivers pick up the slack when older adults are left behind. Their work often goes unnoticed and undervalued while policymakers search for solutions to care for the growing older adult population. The aging population and management of chronic diseases is one of the greatest public health puzzles facing our world today. Family caregiving is the answer for families who cannot afford to place their loved one in a long-term care facility or who's loved one would rather age at home. Family caregiving for older adults can help to alleviate this problem, but this comes at a cost to caregivers' mental health. Supporting family caregiver mental health comes with several interpersonal, emotional, logistical, and financial obstacles to overcome. Stronger, more comprehensive policy solutions would make the lives of family caregivers less stressful, allowing them to provide better care to their loved ones, thus creating a sustainable way to care for the older adult population. This problem's significance to public health lies in the heavy burden that providing consistent and effective care to older adults puts on the healthcare system. As a state harboring a great proportion of older adults, Pennsylvania should pave the way in developing interventions to best support family caregivers and the loved ones they care for. Pennsylvania has enhanced stake in ensuring that older adults and their caregivers are sufficiently supported, which includes providing services and implementing policy that targets family caregiver mental health. In doing so, Pennsylvania can improve care and quality of life for a large portion of its population.

## Table of Contents

|  |           |
|--|-----------|
| <b>1.0 Introduction.....</b>                     | <b>1</b>  |
| <b>2.0 Background .....</b>                      | <b>2</b>  |
| <b>2.1 Family Caregiving .....</b>               | <b>2</b>  |
| <b>2.2 Caregiver Mental Health .....</b>         | <b>3</b>  |
| <b>3.0 Existing Frameworks.....</b>              | <b>6</b>  |
| <b>3.1 Intervention Research .....</b>           | <b>6</b>  |
| <b>3.2 Family Caregiver Support Program.....</b> | <b>7</b>  |
| <b>3.3 RAISE Family Caregivers Act .....</b>     | <b>9</b>  |
| <b>3.4 Other Supports .....</b>                  | <b>11</b> |
| <b>4.0 Discussion.....</b>                       | <b>14</b> |
| <b>4.1 Policy Comparison.....</b>                | <b>17</b> |
| <b>5.0 Recommendations.....</b>                  | <b>19</b> |
| <b>6.0 Conclusion .....</b>                      | <b>23</b> |
| <b>Bibliography .....</b>                        | <b>25</b> |

## **1.0 Introduction**

As science permits people to live longer, the proportion of older adults in the population is steadily increasing. For many countries, including the United States, this is creating a crisis in the economy and in health care. A large population of older adults necessitates a robust work force of people to provide care as well as adequate funds to compensate them. Meeting the demand for care will be no small feat, and the healthcare system needs to find innovative ways to do so. In the wake of severe nurse and medical personnel shortages, nursing and long-term care facilities cannot afford to be overwhelmed further with more residents. Investing in the informal caregiver workforce is necessary to support those performing much needed duties.

Family caregiving has existed for ages; people have always provided assistance to their family members and loved ones. It is a great option for older adults who need care or support, whether that is emotionally, physically, or financially. It allows people to remain in their homes as they age and receive care from a trusted loved one. The United States have enacted a variety of federal and state policies to support family caregivers, many of them addressing the financial burden that they take on. However, family caregivers may also face detriments to their mental health as they juggle their personal lives with their caregiving responsibilities. Caregiving is a stressful, demanding job, and supports should reflect the needs of the caregiving workforce. In addition to the financial and emotional burdens, caregiving can also substantially affect physical health and employment. Pennsylvania should seek to provide services and implement policy to support the mental health of family caregivers of older adults.

## **2.0 Background**

This section will examine the issues that family caregivers of older adults face while contextualizing them within the broader conditions of caregivers and caregiving. The role of a family caregiver comes with emotional and physical labor on a day-to-day basis, making it a difficult job. The COVID-19 pandemic exposed many cracks within the United States' health care system, including caregiving, which brought concerns about family caregivers to light. Awareness of the demands that come with family caregiving for older adults specifically while understanding the context of caregiving today will illustrate the several factors contributing to this issue.

### **2.1 Family Caregiving**

Family caregiving allows older adults to age “in place” and in the care of someone they trust. Family caregivers are defined as “relatives, friends, partners, or neighbors who provide assistance, typically unpaid, to someone who has limitations in their physical, mental, or cognitive functioning” (Schulz). They are highly variable in age, relationship and proximity to the individual, and competence in providing help. As of 2020, one in every five adults in Pennsylvania was a caregiver (BRFSS). Family caregivers provide necessary work and often go underappreciated and underpaid. In Pennsylvania alone, 677,000 family caregivers provide 771 million hours of unpaid care (PDA State Plan on Aging). This work is valued at \$10.1 billion, but family caregivers may go without any financial support to perform their responsibilities, which can often be intense and time consuming. About one third of family caregivers in Pennsylvania

provided over 20 hours of care per week, and over one fifth of them provided care to a person with dementia (BRFSS). Caregivers may spend thousands of their own dollars on their loved one without receiving anything in return.

Family caregivers take on a high financial and emotional burden without sufficient support. As of 2021, an AARP study found that 78% of family caregivers surveyed reported spending \$7,242 per year on average on out-of-pocket costs for caregiving. The need to pay out of pocket on behalf of the care recipient coupled with the time that caregiving may take away from a person's day job can create a significant financial stressor. In recent years, the federal and state governments have introduced policies to compensate family caregivers financially and reduce this burden.

Family caregivers also take on a lot of emotional and psychological stress when they choose to care for their loved ones. They may experience feelings of anxiety, resentment, guilt, or grief due to the caregiving relationship and responsibilities. Nearly half of caregivers surveyed by AARP felt that had no choice but to take on the caregiving role [National Alliance for Caregiving and AARP (2015) Caregiving in the US]. Their duties also leave caregivers with less time to take care of their own mental health, because they are often occupied with the health of the care recipient, potentially putting them at risk for adverse psychological and physical health effects (Schulz). They can suffer from unmet needs in several areas, from leisure, to diet and exercise, but may feel hesitant to leave their loved one without feelings of guilt (Tatangelo, et al).

## **2.2 Caregiver Mental Health**

The mental health of family caregivers should be brought to the forefront of discussions surrounding their contributions and needs. The state of their mental health has an impact on their



ability to care for their loved one in addition to putting an undue burden on their own life. While the caregiver and care recipient may have a close relationship, caregiving requires making many sacrifices. Sacrificing one's own time and energy can put a strain on the relationship between people. It can be incredibly mentally taxing to take on another person's needs as your own. Some psychologists even consider caregiving to be a chronic stress exposure (Schulz). Caring for an older adult with a chronic illness is persistent, unpredictable, and uncontrollable in nature. It can cause physical and psychological stress during the caregiving itself, in addition to secondary stressors in other areas of life. Family caregivers need training, support, and opportunities to engage in meaningful self-care and rest to prevent their role from negatively affecting their mental health (ACL). Several large studies suggest that caregiving, especially when it is high-intensity in nature of hours and duties, can be associated with a greater risk of depression and other mental health issues like caregiver burnout and poorer overall health (Cohen, et al). Informal and family caregivers may also find that they have less time for socializing, which contributes to their lower rates of social participation in addition to increased social isolation and loneliness in contrast with non-caregivers.

Investing in the mental health of older adult family caregivers is in the best interest of the government and the healthcare system. Informal caregivers are the under-recognized heroes of healthcare, and their labor is not valued at the extent that it should be. Family caregivers put in countless hours of work that would otherwise be carried out by nursing facilities, which are already being pushed to their limits. A study conducted by the American Health Care Association/National Center for Assisted Living found that 87% of nursing home providers are facing moderate to high staffing shortages, and 61% of nursing homes have limited new admissions due to these staffing shortages (U.S. News & World Report). Nursing facilities are experiencing extreme strain on their

labor sources and can hardly afford to take on new residents. Family caregivers comprise a vital part of the healthcare workforce, and without them, this strain could be much worse.

It is in the Commonwealth's interest to invest in family caregivers because the government bears some of the costs for nursing facility care. While Medicare does not explicitly cover long term care or a stay in a nursing facility, it does cover medical services within these settings, and Medicaid does provide coverage for qualifying enrollees (AARP). Much of these costs could be saved if family caregivers could provide this care to their loved ones instead. Empowering older adult family caregivers with medical training and mental health resources can enable them to provide more complex care while also prioritizing their own wellbeing (Burgdorf, et al). The Commonwealth would benefit from investing in family caregiver mental health because caregivers are a crucial segment of the healthcare workforce, and it could lead to cost savings on nursing care.

### **3.0 Existing Frameworks**

This section discusses existing frameworks to support older adult family caregivers and those they care for and the literature surrounding them. This includes federal and state policies as well as support services that mitigate stress experienced by family caregivers. These frameworks are not exclusive to family caregivers of older adults but do target specific problems they face. Evaluation of these methods can help create a more complete idea of the outlook for family caregivers of older adults.

### **3.1 Intervention Research**

Abundant research exists on the psychology of family caregiving for older adults to analyze and determine which interventions yield the most benefit. One theoretical framework behind caregiver intervention research is the stress process model (Schulz et al). When caregivers are confronted with stressors such as the functional limitations and problem behaviors of the care receiver, they must determine if these demands pose a threat and if they are capable of adapting to cope with those stressors. Upon perceiving these demands as threatening while also lacking sufficient coping resources, caregivers perceive themselves to be under stress. This perception of stress may manifest negatively, by influencing the caregivers' own psyche and their behavioral and physiological responses within their role. This can also have a reciprocal effect on the older adult they are caring for, if their ability to properly care for them is inhibited by their own psychological distress.

Psychosocial interventions comprise the majority of caregiver interventions, which are based on stress-coping theoretical models. They highlight principles of psycho-education and self-regulation to support caregivers by addressing their information needs, equipping them with adaptive strategies to manage stress, enhance communication between the caregiver and recipient, connect them to additional resources, and provide relevant social supports. Outcomes typically measure indications of morbidity, burden, and stress, in addition to coping skills, social support, and patient outcomes. These studies often focus on disease progression and support for caregivers of older adults with neurocognitive decline, cancer, and stroke. Investment in psychological research of family caregiving is crucial to the understanding of caregiver-care recipient relationships and how those relationships can be supported. This can help public health as a field better understand why there are relational challenges in family caregiving and how they can be mitigated. Informal caregiving has been demonstrated to have a negative impact on the caregivers' well-being and financial stability, so improving caregiver-recipient relationships can help reduce caregivers' overall stress levels and make the role of caregiving more fulfilling (Schulz, et al).

### **3.2 Family Caregiver Support Program**

To better equip family caregivers, the Family Caregiver Support Program provides monetary compensation. This is a federal program that distributes grants to the states to fund support services for family caregivers. The Family Caregiver Support Program aims to encourage healthy and ongoing relationships between caregivers and care receivers. Their main focuses are the well-being of the caregiver, access to respite care, addressing which supports are needed, and financial reimbursement for out-of-pocket caregiving costs.

As this program is delegated by the federal government to the states, each state is responsible for their own Family Caregiver Support Program and may run it slightly differently. In Pennsylvania, the program is administered by the local Area Agency on Aging. Area Agencies on Aging (AAAs) in Pennsylvania act as a link between older adults and their families, and the programs and services they need. They provide information about resources and care providers, assess needs for service, and make referrals to case managers. There are 52 AAAs that serve the Commonwealth's 67 counties. Each caregiver is assigned a care manager who visits the care recipient's home and conducts a needs assessment of the caregiver so that they can work collaboratively to develop a person-centered care plan.

To qualify for the Family Caregiver Support Program, the caregiver and care recipient must both be Pennsylvania residents. The caregiver must be an adult who is primarily responsible for regular care of the recipient, and meet one of three eligibility categories. The first category is specific to older adult care receivers. In the first category, the caregiver is an individual age 18 or older, and the care receiver is an individual age 60 or older with functional deficits or an individual of any age with Alzheimer's or a related disorder, and the caregiver and care receiver are not required to be related or living together. The second and third categories concern dependent children and adults with disabilities, respectively.

There is no financial eligibility for the Caregiver Support Program in Pennsylvania, but the amount of reimbursement is proportional to the total gross income and household size of the care. A sliding scale based on the current Federal Poverty Level (FPL) guidelines is used to decide the percentage of reimbursement. Those who qualify for the program are eligible to receive a variety of services, including care management, benefits counseling, and caregiver education and training. They are also eligible for reimbursement for caregiving-related expenses, such as respite care,

consumable services, supportive services, supplemental services, home modifications, assistive devices, and other services specific to older relative caregivers.

To remove barriers to utilize this program and create more flexibility for caregivers, Governor Wolf signed Act 20 into law on June 11, 2021. This law removes the previous limits on the maximum monthly amount available to a qualified primary caregiver for out-of-pocket expenses they might incur, and the lifetime reimbursement amount for Home Modifications and Assistive Devices. This act designates the Pennsylvania Department of Aging (PDA) as the authority to determine those amounts. As of August 10, 2021, the maximum monthly reimbursement amount increased to \$600 and the maximum lifetime reimbursement amount for Home Modifications or Assistive Devices increased to \$5,000. Act 20 expanded the potential of family caregivers to meet the needs of their loved ones without causing damage to their own finances. The services supported by the Family Caregiver Support Program aim to reduce caregiver stress and depression, thus allowing them to provide care for longer and delaying the need to pursue other long-term services for the older adult. The expansion of this program and its eligibility in Pennsylvania establishes the well-being of older adults and their family caregivers as a priority within the Commonwealth.

### **3.3 RAISE Family Caregivers Act**

Another federal policy targeting family caregivers is the RAISE Family Caregivers Act, which was enacted in 2018. This law addresses the need to develop a national strategy to guide family caregiving. For development and execution purposes, the act establishes the Family Caregiving Advisory Council to provide counsel and identify best practices for supporting family

caregivers. This legislation defines a family caregiver as *an adult family member or other individual who has a significant relationship with, and provides a broad range of assistance to, an individual with a chronic or other health condition, disability, or other functional limitation.* The Council consists of 30 voting members from diverse backgrounds and constituencies, in order to reflect the diversity of those providing and receiving long term care. The Council was tasked with assessing the current state of federal efforts to support family caregivers at the time and recommend changes. In collaboration with the Secretary of Health and Human Services and directors of other federal agencies, the Council developed the National Family Caregiving Strategy to present to Congress.

The National Family Caregiving Strategy seeks to recognize actions taken by the government, providers, communities, and others to support family caregivers. The Council named five core goals as part of the strategy: “expand outreach and education for family caregivers and public awareness of the needs and challenges they face; engage caregivers as partners in providing health care and long-term services and supports for their loved ones; improve access to services and supports such as respite care, counseling and transportation assistance; ensure financial and workplace security for family caregivers; generate research, data and evidence-based practices to develop policies and programs that meaningfully help caregivers.” The strategy identifies a variety of actions, including promoting the implementation of person- and family-centered care in both healthcare and long-term care settings, featuring the care recipient and caregiver at the forefront of the care teams. It also includes the assessment and planning of services to involve family caregivers and care recipients, providing education, training assistance, referral, and care management.

A mechanism for obtaining input on family caregiving issues to guide the National Family Caregiving Strategy was the Request for Information (RFI). This was published in the Federal Register in 2019, and it asked family caregivers and the organizations that support them to express their thoughts and concerns on the topic. Over 1,600 responses were received detailing family caregivers' opinions and highest priority concerns, which included caregiving education and training, respite care, and financial considerations like workplace flexibility (National Academy for State Health Policy). These priorities were taken into the Family Caregiving Advisory Council's consideration when developing the Strategy so that it could accurately reflect the wants and needs of family caregivers.

In the long-term, the National Family Caregiving Strategy should improve equity for family caregivers and care recipients throughout the United States. The variety of proposals and changes represented in the RAISE Act reflects the diversity of types of informal caregivers, each with unique strengths and needs. Each state has different policies regarding financial compensation and other supports for family caregivers and care recipients, but ideally the Strategy will promote adoption of effective policies that put the well-being of these groups at the forefront. The National Family Caregiving Strategy addresses caregiver mental health in its Actions for States, Communities, and Others report. Adoption of these recommendations is crucial for meeting family caregivers' unfulfilled areas of need.

### **3.4 Other Supports**

As a result of the increasing number of family caregivers and the stress that may come with the role, other forms of support now exist. One of these is family caregiver support groups. These



gatherings bring family caregivers into a group setting to share their experiences, find support in other members, and listen to others who may be going through similar situations. Those who are interested can utilize online resources to locate these groups in-person or virtually. Support groups may be geared towards caregivers of someone with a particular condition or can serve family caregivers in general. For example, UPMC offers caregiver support groups for people caring for someone with cancer, dementia, mental health issues, Parkinson's Disease, and stroke.

Support groups have potential to have a significant impact on caregivers' quality of life because they are a voluntary, free coping mechanism (Bernabeu-Alvarez et al). There is evidence that caregiver support groups, especially for those with Alzheimer's and dementia, have a positive impact on caregivers' psychological well-being, burden of stress, social support, and depression. Support groups allow for participants to undergo peer learning, in which they learn from others' experiences. This can help them express emotions they are suppressing, affording them a sense of relief in the support group. The shared experience of exchanging feelings in a support group setting can validate participants' feelings by finding commonalities with others. The socialization within a group can also reduce feelings of loneliness that caregivers might have when much of their time is spent dedicated to their loved one.

Another form of support for family caregivers are medical training programs. Although many caregivers may provide simple care like assisting with activities of daily living and medication management, others may have to adhere to complicated care delivery plans. If the caregiver does not already have a background in healthcare, they should receive training to ensure they are providing care properly. However, less than one in ten family caregivers report receiving any training (Burgdorf, et al). Traditionally, family caregivers are considered to be "informal" care providers are seldom included in the care team or trained to be fully integrated. Training programs

specific to the family caregivers' and the care receivers' needs establishes them as a necessary part of the care team. They can improve caregivers' confidence in their abilities to provide care while also improving conditions for the care receiver by ensuring each provision is performed correctly.

## 4.0 Discussion

Exemplary care for older adults begins with supporting their caregivers. Ensuring that family caregivers have access to supportive resources and feel empowered to use them is essential to improving caregiver mental health. Family caregivers are worthy of increased respect, compensation, and support as they take on a substantial amount of the burden for the United States' healthcare system. Employing supportive services is imperative for giving family caregivers the ability to carry out their responsibilities and remain healthy and happy in their own lives. The three essential parts of the solution to supporting family caregivers' mental health is creating better policy, raising awareness and increasing outreach efforts, and improving upon existing frameworks.

Older adults make up a high proportion of Pennsylvania's population, and the state needs to do more to support them. Pennsylvania ranks 21<sup>st</sup> overall on the AARP Long-Term Services & Supports State Scorecard, and 36<sup>th</sup> for the Support for Family Caregivers category. On the person- and family-centered care indicator, Pennsylvania received a score of 3.7 out of 5.5. There is much room for improvement in these scores, and Pennsylvania should consider what it can do to better serve older adults and their family caregivers.

A variety of avenues exist for supporting family caregivers' mental health. Counseling services are a great way for caregivers to express themselves, and Pennsylvania can incorporate free, accessible, and convenient services to ensure caregivers can utilize them. Medical training is also a necessary part of empowering caregivers to do their jobs well. This can also improve their confidence and perceptions of their abilities to care for their loved one. Training specific to the needs of care recipients would be especially helpful, such as in cases where a family caregiver

provides care for an older adult with dementia or cancer (Tatangelo, et al). Further, Pennsylvania can assist family caregivers in identifying the services they need and help them access them. Navigating the healthcare system and health insurance coverage can be complicated and confusing, and time-consuming on top of the other tasks family caregivers take on. Assistance in these areas as well as with helping them communicate with healthcare providers could reduce the burden on family caregivers.

One area where Pennsylvania falls short is its respite programs. The ability to take breaks, often through the utilization of respite care, is essential for the maintenance of caregivers' mental health and ensuring they can be relieved of that burden from time to time. Respite care can allow caregivers short-term and long-term relief so they are able to rest and live their own lives. States are awarded federal funds in the form of three-year grants to expand their Lifespan Respite Care Programs with the goal of integrating these programs into their system of long-term services and supports. Pennsylvania last received a Lifespan Respite Care Program Grant in 2010. Respite programs are invaluable resources to older adults and their caregivers and are a centralized way to access help. The Lifespan Respite Care Programs work to improve the existing respite care infrastructure by enhancing services, streamlining access to care, filling in service gaps, and overall improving the quality of services available. By receiving more funding and expanding their Lifespan Respite Care Programs, Pennsylvania can reduce the burden on family caregivers for older adults by giving them a break.

In order to access services and supports, family caregivers of older adults need to be made aware that they exist. An issue with determining the needs of family caregivers is that many of them may not identify as or think of themselves as a caregiver, which can result in them not being counted in data collection efforts (National Strategy for Family Caregiving). Rather, they consider

themselves a child, spouse, friend, neighbor, or family member. This can explain why family caregivers of older adults may not access the resources available to them, because they think of their work as simply doing what must be done to care for their loved one. Therefore, it is important to engage all sectors in creating a system to support family caregivers. In doing so, employers can learn how to best support their employees that provide informal care to a loved one. This can create a network of support among employers and employees that acts as another layer of protection for family caregiver mental health. According to the RAISE Act Family Caregiving Advisory Council, family caregivers themselves will feel comfortable asking for and accessing support only when caregiving is widely recognized as a universal life experience. Acknowledging the realities of family caregiving for all people and offering services to the many Americans that will find themselves as family caregivers can uphold a network of support.

Successful outreach is vital for connecting family caregivers to the necessary supportive resources available to them. Expanding outreach efforts also has equity implications, as those in immigrant and multicultural communities may have caregivers with limited English proficiency (National Strategy for Family Caregiving). One way for Pennsylvania to go about this is by configuring the state's caregiver support program to improve outreach to underserved populations in particular. This could involve budgeting for the translation and interpretation of materials and events that benefit family caregivers of older adults. Pennsylvania can also target these materials and events to specific locations and populations to ensure that family caregivers of all racial/ethnic backgrounds and socioeconomic statuses are able to access support.

## 4.1 Policy Comparison

According to the Long-Term Score Card, Pennsylvania falls in the third quartile of the country in its family caregiver support ranking. Other states in the region certainly performed similarly, or worse, such as Ohio and West Virginia. However, other nearby states, including, Maryland, New York, and New Jersey, were ranked in the second and top quartiles. In order to determine how Pennsylvania can use policy to do better for older adult family caregiver mental health, it is important to look at how other states are doing so.

The Support for Family Caregivers dimension consists of four indicators: Supporting Working Family Caregivers, Person- and Family-Centered Care, Nurse Delegation and Scope of Practice, and Transportation Policies. These indicators do not directly evaluate mental health supports, but mental health is implicated in the extent to which caregivers are supported in other ways. Each of these factors can impact the mental health of the family caregiver – for example, if family caregivers are not supported in their jobs and allowed to take time away to care for their loved one, this can cause stress and strain on their mental health (Schulz, et al). Improving Pennsylvania’s standing in each of these indicators can indirectly benefit family caregiver mental health. That said, the Long-Term Score Card should add an indicator to assess how well each state directly supports family caregivers’ mental health through its policies and services offered. Further, AARP recommends that states conduct additional surveys among family caregivers of older adults to streamline the research into their needs. Carrying out such assessments could allow states to identify what family caregivers truly need and how they can best feel supported in their mental health. This information could then be used to make recommendations to governing bodies.

As they seek to expand policy efforts to support family caregiver mental health, Pennsylvania lawmakers can look to other states successes for ideas. While there may be some

demographic differences between the Commonwealth and other states that perform better, Pennsylvania can adapt successful programs to its own population and resources. Respite care programs, availability of paid leave for caregivers, and awareness campaigns are all potential areas that lawmakers could analyze and determine to implement in Pennsylvania.

## 5.0 Recommendations

Several changes are necessary to improve conditions for family caregiver mental health in Pennsylvania. This includes enacting policy to support caregivers, raising awareness and expanding outreach, and strengthening existing frameworks. Mental health and family caregiving for older adults are both complex, far-reaching problems, and thus need a comprehensive approach in their solutions. The Commonwealth should focus on the implementation of recommendations outlined in the National Strategy to Support Family Caregivers. These recommendations were created to directly improve the wellbeing and support of family caregivers, and many of them can be implemented simply and feasibly. Pennsylvania can and should enact new policy to provide family caregivers of older adults ample options to maintain their mental health while performing their duties. In a perfect world with unlimited resources, Pennsylvania would establish a Caregiver Mental Health Task Force which would seek out specific actions to directly address the problem and its symptoms, and implement sweeping policy to support family caregiver mental health through social and financial efforts. However, such investment would require incurring substantial costs in addition to political power and coordination of groups with converging interests. Instead, incremental but productive policy work is necessary in addition to other supplementary action. These goals are more attainable in the short-term, and would still efficiently use the Commonwealth's limited resources.

A variety of policies can contribute to improving the mental health of family caregivers. One possible policy solution is introducing paid leave for family caregivers to prevent them from missing out on wages due to their caregiving duties. Missed wages can contribute to the stress that family caregivers face, and alleviating this problem has potential to improve their mental health.



Proposed in 2021, President Biden’s American Families Plan offered a national paid family leave and medical leave program. It would have ensured 12 weeks of paid family, medical, or personal leave for caregivers to bond with a new baby, care for a family member, or grieve the loss of a loved one. Family caregivers of older adults could utilize their paid leave time to provide care directly, or accompany their loved one to a medical appointment. While the American Families Plan did not pass, some states already have similar programs to assist people through stressful times by preventing missed wages. A 2017 study in California found that their paid leave program was associated with an 11 percent reduction in elderly nursing home usage (Arora). Therefore, paid leave enabled family caregivers of older adults to provide care for their loved ones rather than turning to nursing home care. Paid leave is an attractive program, in part because it allows for cost savings for both families and the state. Enacting such a policy would provide relief to the thousands of Pennsylvanians who act as family caregivers. This is not an end-all, be-all way to improve family caregivers’ mental health, but it does constitute a step in the right direction.

Another policy to consider is finding ways to provide mental health care coverage to ensure that family caregivers have access to affordable, reliable, high-quality mental health services. The Family Caregiver Alliance estimates that approximately 20 percent of family caregivers suffer from depression, and while caregiving may not cause depression directly, caregiving can come with extreme mental and emotional strain. Therapy and counseling resources are important for anyone experiencing depression, but family caregivers could benefit from receiving special coverage for mental health care. Ensuring that family caregivers have access to counseling could help them manage symptoms of depression and reduce the strain from caregiving (Family Caregiver Alliance).

In order to access needed supports and services, it is important that family members that provide care view themselves as official, legitimate “caregivers,” who are deserving of this access. Doing so would include them as a key member of a patient’s care team, ensuring they are part of communication and decision making for their loved one. Raising awareness regarding the work that family caregivers do is the first step in bringing valuable support to those that need it. Pennsylvania can utilize its state departments of health and human services in addition to its seven county HHS departments and four municipal HHS departments to launch awareness campaigns at the state and local levels. Along with assistance from local government entities, community leaders and gathering places, healthcare facilities, and school districts as points of contact, HHS departments can use these campaigns to connect older adults and their caregivers to necessary resources. These campaigns could also focus on raising awareness among the community who may not be fully aware of the scope of work that family caregivers provide. This awareness could help family caregivers feel seen, supported, and appreciated. This is essential for those who may not feel comfortable asking for help until it is offered to them and they feel empowered to do so.

Pennsylvania already has a framework of supports for family caregivers, and strengthening them is a feasible way to eliminate a greater portion of unmet needs. Pennsylvania has already made strides in adopting important legislation and programs to support family caregivers. To strengthen these existing frameworks, the Commonwealth can fund Home and Community Based Services, which can be used to balance Medicaid while also offering flexibility in allowing older adults to pay for direct care and covering respite services. Expanding upon the ability to use HCBS funds to supplement supports for older adults while continuing to innovate and find new pathways to pay for family caregiver supports could make a difference in their experiences. Further, national research infrastructure does not take in the full scope of caregiving, and even in modules that do

like the BRFSS caregiver module, there is a lack of focus on mental health and recognition of all types of caregivers. Such research could investigate new ways to support caregiver mental health based on the opinions of those with the most at stake.

## 6.0 Conclusion

It is evident that we cannot effectively support older adults without supporting their caregivers. To meet the needs of older adults, their family caregivers must feel empowered to take on their role. Pennsylvania can follow the lead of other states by enacting progressive policies aimed at improving the wellbeing of family caregivers and consequently the care of older adults. The Commonwealth along with the communities within it can strive to reach these goals by enacting policy to support caregivers, raising awareness and expanding outreach, and strengthening existing frameworks.

Family caregivers are not superhuman despite the wide variety of roles they may take on. Their work is certainly admirable and noble, but they do not always have a choice, and it requires maintaining a difficult balance of roles. Family caregivers for older adults may enjoy spending time with and caring for their loved ones, but this does not mean they do not have other priorities or need their own time and space. They deserve to feel seen, appreciated, and supported as care providers so that they can access necessary services and maintain their mental health.

The future appears to be hopeful for family caregivers of older adults. Several initiatives are playing out over the next year that will improve the outlook for caregiver supports, including mental health. Most recently, President Joe Biden signed 50 executive orders aimed at strengthening care infrastructure. The administration will better reflect the National Strategy to Support Family Caregivers with its actions to “recognize and support family caregivers in healthcare settings, expand respite support for America’s 11 million dementia caregivers, and strengthen mental health supports for the caregivers of military veterans” (National Alliance for Caregiving). These actions will help to address the emotional distress, in addition to other

consequences, that caregivers face, and provide hope that policy to support family caregivers is moving in a positive direction.

## Bibliography

- AARP. (n.d.). *Long Term Services & Supports State Scorecard*. Pennsylvania State Scorecard - The Commonwealth Fund. Retrieved March 16, 2023, from <https://www.longtermscorecard.org/databystate/state?state=PA>
- Beach, S. R., Schulz, R., Donovan, H., & Rosland, A. M. (2021). Family Caregiving During the COVID-19 Pandemic. *The Gerontologist*, *61*(5), 650–660. <https://doi.org/10.1093/geront/gnab049>
- Bernabéu-Álvarez, C., Lima-Rodríguez, J. S., & Lima-Serrano, M. (2021). Effect of support groups on caregiver's quality of life. *Family Process*, *61*(2), 643–658. <https://doi.org/10.1111/famp.12684>
- Burgdorf, J. G., Arbaje, A. I., Stuart, E. A., & Wolff, J. L. (2021). Unmet family caregiver training needs associated with acute care utilization during home health care. *Journal of the American Geriatrics Society*, *69*(7), 1887–1895. <https://doi.org/10.1111/jgs.17138>
- Cohen, S. A., Nash, C. C., & Greaney, M. L. (2021). Informal caregiving during the covid-19 pandemic in the US: Background, challenges, and opportunities. *American Journal of Health Promotion*, *35*(7), 1032–1036. <https://doi.org/10.1177/089011712111030142c>
- Commonwealth of Pennsylvania. (n.d.). *HealthChoices*. Department of Human Services. Retrieved March 16, 2023, from <https://www.dhs.pa.gov/healthchoices/Pages/HealthChoices.aspx>
- Family Caregiver Alliance. (n.d.). *Caregiver depression: A silent health crisis*. Caregiver Depression: A Silent Health Crisis - Family Caregiver Alliance. Retrieved April 10, 2023, from <https://www.caregiver.org/resource/caregiver-depression-silent-health-crisis/>
- Mollica, M. A., Smith, A. W., & Kent, E. E. (2020). Caregiving tasks and unmet supportive care needs of family caregivers: A U.S. population-based study. *Patient Education and Counseling*, *103*(3), 626–634. <https://doi.org/10.1016/j.pec.2019.10.015>
- Nadash, P., Tell, E., Regan, C., Jansen, T., Alberth, A., & Cohen, M. (2021). Findings From RAISE Act Research: Family Caregiver Priorities. *Innovation in Aging*, *5*(Suppl 1), 63–64. <https://doi.org/10.1093/geroni/igab046.243>
- National Academy for State Health Policy. (2023, January 10). *What family caregivers need: Findings from listening sessions*. NASHP. Retrieved April 10, 2023, from <https://nashp.org/what-family-caregivers-need-findings-from-listening-sessions/>

- The Recognize, Assist, Include, Support, and Engage (RAISE) Act Family Caregiving Advisory Council & The Advisory Council to Support Grandparents Raising Grandchildren , 2022 National Strategy to Support Family Caregivers: Actions for States, Communities, and Others 1–37 (2022). Administration for Community Living.
- Schulz, R., Beach, S. R., Czaja, S. J., Martire, L. M., & Monin, J. K. (2020). Family Caregiving for Older Adults. *Annual review of psychology*, *71*, 635–659. <https://doi.org/10.1146/annurev-psych-010419-050754>
- Schulz, R., & Czaja, S. J. (2018). Family Caregiving: A Vision for the Future. *The American journal of geriatric psychiatry : official journal of the American Association for Geriatric Psychiatry*, *26*(3), 358–363. <https://doi.org/10.1016/j.jagp.2017.06.023>
- Schulz, R., & Sherwood, P. R. (2008). Physical and mental health effects of family caregiving. *The American journal of nursing*, *108*(9 Suppl), 23–27. <https://doi.org/10.1097/01.NAJ.0000336406.45248.4c>
- Tatangelo, G., McCabe, M., Macleod, A., & You, E. (2018). “I just don’t focus on my needs.” the unmet health needs of partner and offspring caregivers of people with dementia: A qualitative study. *International Journal of Nursing Studies*, *77*, 8–14. <https://doi.org/10.1016/j.ijnurstu.2017.09.011>
- U.S. Department of Health & Human Services. (n.d.). *RAISE Family Caregiving Advisory Council*. ACL Administration for Community Living. Retrieved March 16, 2023, from <https://acl.gov/programs/support-caregivers/raise-family-caregiving-advisory-council>
- U.S. News & World Report. (2022, June 29). *Staffing shortages have U.S. nursing homes in crisis - US news*. U.S. News & World Report. Retrieved April 1, 2023, from <https://www.usnews.com/news/health-news/articles/2022-06-29/staffing-shortages-have-u-s-nursing-homes-in-crisis>