

Caring for the Caregivers:

The Case for Respite Services in Pennsylvania

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Letter from the co-chairs

Family caregivers have always been a vital source of support for older adults, adults with disabilities, and children with special health needs, and their role in the care system has become increasingly critical over the past several decades. As long-term care has continued to shift away from nursing homes and residential facilities towards home and community-based services, family homes have become de facto clinical care settings where caregivers are performing myriad nursing or medical tasks once provided by licensed professionals. Often times, this care is provided without sufficient education, training, or support and by individuals who are also facing various employment and childcare responsibilities. Without supportive systems in place, these caregivers face unemployment, long-term financial strain, and serious impacts to their physical, emotional, and psychological health.

As elected officials in Southwestern Pennsylvania, we take seriously our duty to uplift our residents and ensure they have the means to care for both themselves and the most vulnerable members of our community. So in 2023, we convened a fresh slate of IOP Health and Human Services Policy Committee members and kicked off the first meeting with one simple question: how has family caregiving impacted you? Without hesitation, every member recounted a story that has, in one way or another, been reflected in this report. Whether it was stepping in to support aging parents in failing health, taking leave to care for a newly disabled spouse, or struggling to find paid help to increase a family member's independence, the running theme was the same: nearly all of us will struggle with the realities of caregiving and will require help to do it well.

As the committee began tackling this critical issue, it took time to narrow the focus. The truth is, the paid and unpaid, formal and informal arms of the caregiving system are so interconnected that positively affecting one often necessitates changes to another. Ultimately, we wanted to pursue a path with the greatest potential for immediate, tangible impact on vulnerable families in the region. Eventually, this path led us to informal respite care networks.

Woefully underutilized, respite care provides short-term supervision for a care recipient so that their family caregiver can be temporarily relieved of their caregiving duties. There are many forms of respite but this report focuses on those informal, volunteer, and faith-based programs that do not rely upon direct care workers or state and federal funding to give caregivers a break. These services can be as structured as a university-based volunteer program or as casual as a local congregation offering companion services in a family's home. They can spring out of any community, no matter the size or number of resources, and operate based on the need of local residents.

While we know that informal respite care is not sufficient to totally support family caregivers on its own, it can be a powerful mechanism that withstands direct care workforce shortages, fluctuations in funding, and the shifting care needs of our older and disabled populations. The following report offers an abundance of information on successful models and mechanisms that support the creation and sustainability of these programs, and we hope that it will serve as a blueprint for implementing similar success in the commonwealth.

Nearly all of us will be given the opportunity to care for a family member and feel blessed to do so; but we cannot do it alone. As the co-chairs of this committee, we hope that this report can inspire leaders at all levels of government to ensure that the Pennsylvanians serving as the backbone of the long-term care system are given the tools, guidance, and support they need to continue to do so.



Dan Frankel
State Representative, 23rd District
Majority Chair, House Health Committee



Leslie A. Osche
Chairman, Board of Commissioners
Butler County



Introduction

Purpose and Scope

The purpose of this report is to inform the public of the current state of family caregiving in Pennsylvania and provide several recommended strategies for improving caregiver access to respite care networks at the state, local, and community levels.

Specifically, this report will:

- Detail the policy landscape of family caregiving issues in Pennsylvania
- Provide a background on respite care and the role of Medicaid and Medicare in these networks
- Highlight innovative respite practices from other states that have informed the committee's recommended strategies and next steps.

The Institute of Politics Health and Human Services Policy Committee (IOP HHS Committee), co-chaired by Butler County Commissioner Leslie Osche and State Representative Dan Frankel, Majority Chair of the House Health Committee, determined it was critical to include caregivers of all vulnerable populations in the report's scope, as they are served by many of the same support systems and rely on the same resources. These populations include:

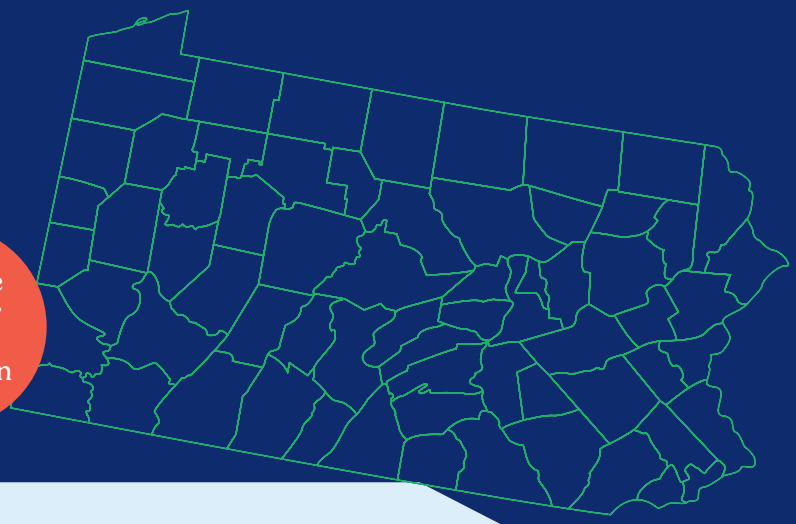
- Older adults
- People with disabilities
- Children with special medical needs.

In examining the caregiving landscape, the following impacts became increasingly clear:

- The toll taken on a wide swath of middle-income American families
- Impacts on employers, state budgets, and Medicaid
- Impacts on Pennsylvania's economy overall.

1 in 4 (3.4 million) Pennsylvania residents is **over 60 years of age.**

5th in the nation for the 60+ population



Pennsylvania's Tipping Point

In Pennsylvania, the caregiving crisis has reached a critical inflection point, requiring urgent attention from policymakers at every level.

- More than 2.3 million adults in Pennsylvania provide care to a family member with complex medical conditions or disabilities, comprising 23% of adults across the commonwealth, and the share of Pennsylvanians shouldering caregiving responsibilities continues to grow.[1]
- Nearly half of Pennsylvania family caregivers are high-intensity caregivers, providing more than 40 hours of care weekly, and four in ten have experienced at least one negative financial impact because of their care responsibilities.[2]
- While four in ten family caregivers would find respite care helpful, nine in ten have never used such services — pointing to a significant and largely unmet need.[3]
- Pennsylvania's rural counties face compounding pressure: with an aging population and a declining labor force participation rate, labor shortages will likely continue even as demand for aging services, especially health care, increases. This phenomenon causes a ripple effect in which family caregivers leave the workforce, impacting economic growth, especially in rural Pennsylvania.[4]
- Pennsylvania is already stretched for in-home care providers, with more than 112,000 direct care shifts going unfilled in the state each month — a gap that will only widen as 1 in 3 Pennsylvanians is expected to be over the age of 65 by 2030.[5]

Taken together, these trends underscore the urgent need for coordinated, bipartisan action and innovation to strengthen Pennsylvania's respite care and family caregiving support systems before the demand becomes unmanageable.

What is Family Caregiving?

Family caregiving means providing unpaid and often untrained support to loved ones or relatives who require care due to aging, disabilities, or complex medical conditions.

1 in 4 American adults are caregivers

70% of working-age caregivers **are employed** while caregiving for loved ones.

The number of family caregivers has increased significantly in recent years. Across the country, 63 million adults are now providing unpaid care for family members — a 45% increase over the past 10 years — and 1 in 4 American adults are caregivers. Of this total, four million are caring for children under age 18, and 59 million are caring for adults.[6]

Care recipients represent a broad spectrum of ages and conditions. Most caregivers report supporting someone in their 70s, and the care recipients often exhibit multiple health conditions. The top three conditions reported by caregivers are "old age" (13%), dementia (11%), and mobility concerns (8%); together, these comprise about a third of the conditions cited by caregivers as the main reasons for care.[7] Other conditions requiring care include mental health and substance use disorders, developmental or intellectual disabilities, and behavioral diagnoses. Younger caregivers (ages 18-49) are nearly twice as likely as older caregivers (50 and up) to provide care for these issues.[8]

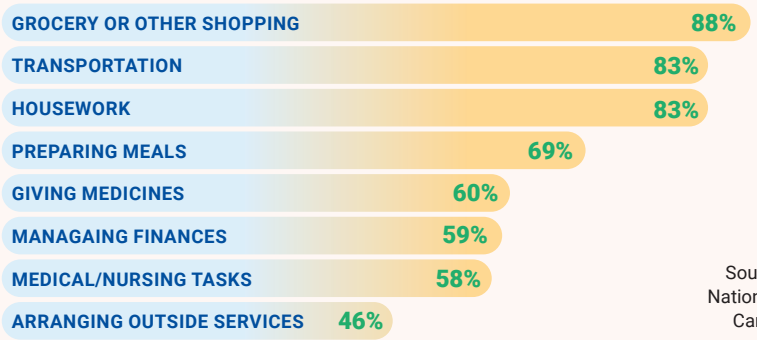
1 in 5 caregivers live in rural areas.



Caregivers vary in age, and recent reports show today's caregivers are younger than ever. **Nearly 1 in 3 (29%) of caregivers fall into what is now referred to as the sandwich generation, meaning they juggle raising their minor children while simultaneously caring for adult relatives.** More women identify as caregivers than men, with 61% of women serving in this role versus 38% of men, and 1 in 5 caregivers live in rural areas.[9] Seventy percent of working-age caregivers, ages 18 to 64, are employed while also caregiving for loved ones.[10]

Caregiving demands have grown in terms of intensity, the share of caregivers' time spent caring for loved ones, and the duration of time spent caregiving. Given that care recipients often face multiple conditions, demands on caregivers have become increasingly complex; caregivers must adapt and remain nimble in building their skills. Basic caregiving tasks range from helping a loved one manage medications to providing light housekeeping.[11] These are known as instrumental activities of daily living, or IADLs, and 84% of caregivers report helping loved ones with three or more of these tasks.

PA Family Caregivers Help with Many **Instrumental Activities of Daily Living**



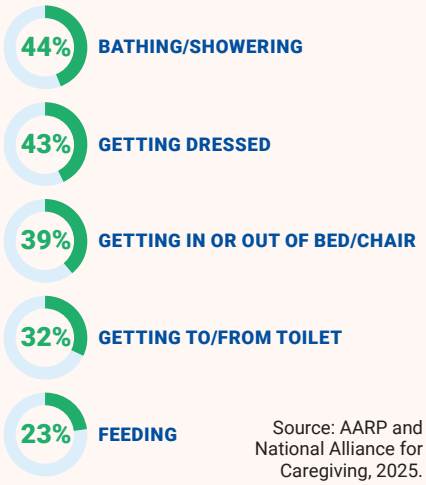
Source: AARP and National Alliance for Caregiving, 2025.

More intense tasks, known as Activities of Daily Living, or ADLs, can be physically demanding, and 23% of caregivers report difficulty.[12]

Caregivers also provide nursing tasks that would typically be administered by a healthcare professional, such as managing catheters, giving injections, and monitoring vital signs. While more than half of caregivers perform these tasks, **only 22% have received training from healthcare professionals.**[13] Recent data show that the average length of caregiving is 5.5 years.[14]

> *"I hear many people talk about it as a privilege, but it definitely comes with costs, with lost opportunities."* — *Disability Policy Director, U.S. Senate*

PA Family Caregivers Help with Many **Activities of Daily Living**



Source: AARP and National Alliance for Caregiving, 2025.

More than half of caregivers report that their responsibilities make it difficult to manage their own mental health.



Caregiving, while rewarding, comes with physical, emotional, and financial implications. For the first time, researchers collected national data evaluating the health of caregivers themselves, revealing that 1 in 5 caregivers report "fair or poor health" as a direct result of their caregiving roles.[15] Caregivers from all demographics experience sleep deprivation, lack of exercise, poor nutrition, failure to rest when they themselves are sick, and putting off or missing their own medical appointments. Caregivers also face an increased risk of substance use disorders.[16] Nearly half of caregivers report experiencing moderate or high physical strain,[17] and two thirds report moderate or high emotional stress. More than half of caregivers report that their responsibilities make it difficult to manage their own mental health, with caregivers ages 18-34 most likely to report suffering from anxiety.[18] Financial implications include negative impacts on caregivers' ability to work; nearly 25% of unemployed caregivers (24%) and retired caregivers (22%) report that they have been unable to enter or re-join the workforce because of caregiving demands. Working caregivers report negative impacts on their career, such as taking unplanned time off work, reducing regular work hours, and passing up opportunities for promotions. More than two thirds of caregivers report personal financial strain as a result of caregiving, including inability to save, accumulating credit card debt, missing mortgage payments, and raiding retirement savings to remain fiscally afloat.[19]



A broad swath of the population, especially middle-income families, are forced to spend down savings to qualify for Medicaid to finance long-term care. The population impacted continues to grow, with one study projecting 16 million middle-income individuals age 75 and over being likely to wind up on this track by 2033.[20]

This report further articulates the physical, emotional, and financial impacts caregivers face as they navigate caring for loved ones within the fragmented long-term care system in the commonwealth and the U.S. as a whole in the next section.

What is Respite?

Respite care is short-term care provided to a care recipient so that their family caregiver can have temporary relief from care duties, and is generally acknowledged as an effective tool to support family caregivers.[21]

Given the demands and implications of caregiving, respite care is an important tool to allow caregivers to care for their own needs. Despite this, respite care is widely underutilized. Recent data shows nearly 40% of caregivers report that respite services would help, but only 13% actually use these services.[22] This chronic underutilization can be attributed to cost barriers, emotional influencers such as guilt, as well as a lack of awareness about available programs.

Learning Where to Focus

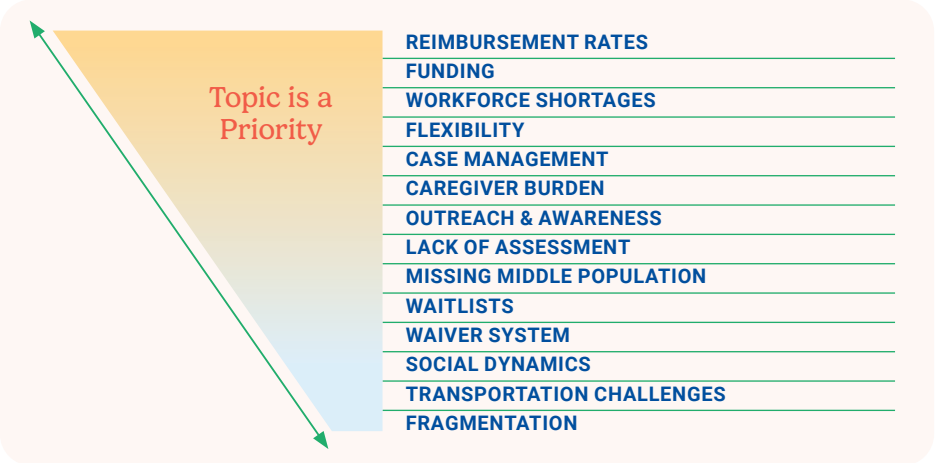
Beginning in February 2023, the IOP HHS Policy Committee held a series of meetings to understand the issues facing family caregivers across Southwestern Pennsylvania, assess the current state of respite care in the region, and develop strategy and policy recommendations to improve the systems of support for our vulnerable families.

As this work progressed, the committee developed another goal — to understand the availability, utilization, and accessibility of respite care in Pennsylvania, as well as barriers and recommendations for improvements at the state, local, and community levels. Throughout this process, the committee recognized that while the needs of care recipients among various populations differed, the needs of caregivers were similar, and respite care addresses a common need.

> The purpose of respite care, and its impact on the caregiver, is the same regardless of care recipients' conditions.

In conducting this project at the direction of the committee, the IOP leveraged the expertise of committee members and utilized the following: research, including a literature review and policy scans; data collection; and analysis of relevant local, state, and federal laws. Once the focus of this work turned to respite care, the IOP conducted a series of stakeholder interviews with academic researchers, practitioners, state and local officials, United States Senate staff, and program administrators. Interviewees were asked about barriers to access and other issues facing the respite care system.

The IOP then conducted a thematic analysis based on interview transcripts; a brief summary of the results of this analysis can be found below:



Family Caregiving in Pennsylvania



With over 1.49 million Pennsylvania family caregivers providing more than 1.39 billion hours of care[23] to their older and disabled family members it comes as no surprise that providing adequate support to these families has been prioritized by many policymakers, organizations, and the IOP's HHS Policy Committee.

> *"The stressors and demands on the family members don't follow a 9-5, Monday through Friday calendar."*
> *— Disability Policy Director, U.S. Senate*

Family caregiving in Pennsylvania encompasses care for older adults, people with disabilities, and children with special medical needs. While there is a lack of precise data distinguishing how many caregivers support non-dementia disabilities, the total number of unpaid caregivers includes many supporting individuals with developmental, physical, and intellectual disabilities. Despite the disparity in available data, the committee felt it was crucial to include caregivers of all vulnerable populations as they are served by many of the same support systems and rely on the same resources.

Due to the availability of data related to older adults, we know that one in four (3.4 million) Pennsylvania residents is over 60 years of age, placing the commonwealth fifth in the nation for the 60+ population. As this number continues to rise to an estimated 4 million by 2040 and metrics like birth rates continue to fall, this demographic shift will have far reaching implications for the commonwealth's healthcare system, workforce, and economy.[24]

The vast majority of older Americans wish to age in place in their communities, and more than half will require long-term services and supports (LTSS) to do so. Unfortunately, few have the capacity to finance long-term care (LTC) at home for themselves or a loved one, thus shifting the burden to unpaid, untrained friends and family.[25] This burden is expected to become even greater over the next several years due to policy changes at the federal level, delayed childbearing, and geographically dispersed families, all of which will contribute to Pennsylvania's looming care gap.[26]



How Did We Reach this Tipping Point?

To understand how we got here, we first have to look at the evolution of Medicaid and Long Term Support Services (LTSS) in the U.S.

Medicare, Medicaid, and Limited LTSS Coverage

Although Medicare is the primary insurance system for older adults and younger people with disabilities, it actually provides very little coverage for long-term care, including LTSS which encompass the range of medical, personal care, and social services that may benefit an older adult, person with disabilities, or individual with other chronic health conditions; the Administration for Community Living (ACL) estimates that 69% of people will use LTSS during their lifetime. As the primary payer for these services, Medicaid spending and regulations have the greatest impact on LTSS populations.[27] While Medicaid is the primary payer for 63% of long-term care residents, and 23% of nursing facility residents use an alternate financing option, such as paying out-of-pocket, recent polling shows four in 10 adults erroneously believe Medicare is the primary payer for institutional long-term care coverage. In fact, Medicare is the primary payer of coverage for only 14% of long-term care residents.[28]

When the Medicaid program was created in 1965, states were required to provide medically necessary nursing facility care for most eligible individuals. But over the past several decades, states have used federal authorities and federally funded grant programs, such as 1915(b) and (c) waivers that suspend normal Medicaid rules in favor of greater service options for broader populations, to develop a broad range of home- and community-based services (HCBS) that enable a beneficiary to receive care in their home or community as an alternative to institutionalization. **Driven in large part by individuals with disabilities and their caregivers, this shift to HCBS was and still is consistent with many Medicaid enrollees' preference of where they would like to receive their care.**[29]

The Shift Toward Home- and Community-Based Services (HCBS)

HCBS, which include home health, adult day health, personal care services, case management and more, allow individuals to remain in their home or community instead of going to an institution for care. While these services were not originally a priority for Medicaid, the bias towards institutional care eroded over time and Medicaid spending on HCBS officially surpassed institutions in 2013.[30] This rebalancing of the LTSS system in the U.S. was further accelerated by the COVID-19 pandemic as states developed an even greater interest in promoting the use of services that avoid institutional settings.[31]

This is where family caregivers come in.

Critical to Medicaid agencies' effort to eliminate institutional bias, family caregivers play an important role in helping enrollees fulfill their preference to remain in the community. By assisting their older and disabled loved ones with activities of daily living, personal care, transportation and more, caregivers help offset the cost of paid personal care services and delay or prevent the need for costly hospitalizations and nursing facility admissions.[32]

The Result: A Critical Misalignment

But while the majority of Medicaid beneficiaries and their families prefer this care delivery system, it does not come without some difficulties. As healthcare has increasingly shifted to non-institutional settings, many homes have become de facto clinical care sites where caregivers are performing myriad nursing or medical tasks that would have been provided by licensed professionals in the past. Further, advances in medicine that save and extend lives have increased the duration, complexity, and technical difficulty of care required by older and disabled Pennsylvanians.[33] And while families frequently report that this experience is rewarding, it can still leave caregivers emotionally, physically, and financially depleted.[34]

Impact on Caregivers

While many family members may not recognize or identify with the term "caregiver," instead viewing their duties as part of their familial role, a compelling body of evidence suggests that many experience negative emotional, physical, and financial effects as a result of their role. Evidence also indicates that many caregivers receive inadequate preparation for the tasks they are expected to carry out, and report feeling marginalized in the delivery of healthcare and LTSS.[35]

The Financial Toll of Caregiving

As far as economic impacts, one in five family caregivers report high financial strain as a result of caregiving; three in 10 have stopped saving and one in four have even taken on more debt.[36] **One study found that 78% of family caregivers incur out-of-pocket expenses, spending an average of $7,000 per year.**[37]

1 in 5 family caregivers report high financial strain as a result of caregiving



As caregivers increasingly provide care for more than five years, the majority report suffering at least one employment-related impact[38] and over half are employed hourly.[39] As hourly work often comes with less money and fewer benefits and employment protections, many caregivers have had their hours cut or were forced to leave the workforce entirely.[40] Women and minority caregivers have also been shown to provide more frequent care and, as this demographic is more likely to be employed hourly, they often experience job impacts at a higher rate.[41]

These financial impacts can persist even once the care recipient has moved to a long-term care facility as the inability to remain in the workforce, even temporarily, can jeopardize income, job security, personal retirement savings, eventual social security retirement benefits, career opportunities, and overall long-term financial well-being that can negatively affect future generations as the caregivers themselves age.[42]

40% of family caregivers cited the emotional stress of balancing caregiving and work as their biggest challenge.



Emotional and Physical Health Toll

Beyond the financial implications, family caregivers often suffer emotional and physical consequences as a result of the care they provide. For example, in one study, 23% of respondents found it difficult to care for their own health and 60% reported that caregiving has made their health worse.[43] Another study found 40% of family caregivers cited the emotional stress of balancing caregiving and work as their biggest challenge.[44]

As the availability and adequacy of family caregiving is often simply assumed, very little assessment, training, and support is offered to individuals who are trying to provide care, determine benefits eligibility, and navigate complex social services systems for a loved one. In fact, only 29% of caregivers report being asked by a healthcare professional about their caregiving needs and the majority say they lack adequate training for medical and nursing tasks that receive little to no implementation monitoring over time.[45] Not only does this marginalization put additional pressure on stressed caregivers, but it jeopardizes the health and well-being of vulnerable older adults as well.

While the fragmented health and LTS system is frustrating, stressful, and costly to navigate, research has shown that when caregivers receive assistance that is appropriate to their needs, both they and the care recipient experience improvements in well-being and quality of life.[46]

> *"No one makes their best decision while under constant stress."*
>
> *— MaryJo Caruso, Former Director of CareBreak Respite Care Program, Sewickely, PA*

Impact on Medicaid and State Spending

Given that Medicaid is the primary payer for long term care overall, and covers 63% of nursing facility residents, preventive measures such as respite care can be used to reduce Medicaid spending and alleviate strain on state budgets, while keeping employees who are family caregivers in their jobs.

As explained in the introduction, the growing phenomenon of middle-income Americans, spending down savings to pay for long-term care out-of-pocket, in order to eventually qualify for Medicaid to cover care, poses future challenges to already tight state budgets.

Return on Investment

- Because respite care delays and can eliminate entirely the need for institutionalization and costly hospitalizations, which most often are paid for by Medicaid coverage, this temporary care can curtail Medicaid and state spending.
- Family caregivers are sustained by short-term breaks provided by respite care. Reduction in burnout allows caregivers to remain in the workforce.

The Role of Direct Care Workers

While individuals with personal assistance needs rely first and foremost on family members and friends, and only one in three family caregivers report utilizing paid help, 234,000 direct care workers (DCWs) provide a variety of critical assistance and supports to older Pennsylvanians.[47]

> *"This industry is accustomed to really just absorbing the cost of inflation changes on an annual basis without getting reimbursement adjustments."*
>
> *— Mia Haney, CEO of the Pennsylvania Homecare Association*

The care provided by DCWs and family caregivers is inextricably linked and research shows that each member of this care team often sets the stage for the other's success.[48] While family caregivers often provide aides with critical information about their family member's specific needs and preferences, DCWs offer essential support that enables the unpaid caregivers to better manage their personal and professional responsibilities.



The growing population of older adults, and dwindling availability of family caregivers, has driven up demand for homecare workers and this workforce is projected to **increase by 37% over the next decade.**

Unfortunately, the longstanding recruitment and retention challenges in this field have been exacerbated by the COVID-19 pandemic as LTC employers compete with employers from other industries that can offer higher wages in a fairly competitive labor market.[49]

Even though the role of a DCW requires considerable technical ability and an extensive set of interpersonal skills, wages and earnings are persistently and notoriously low for this workforce. While incremental wage growth has occurred as a result of federal and state investment over the past 10 years, the median hourly wage in Pennsylvania remains $13.35[50] and the median annual earnings across the country are only $21,700.

These low wages, combined with a high rate of part-time work, makes it extremely difficult for DCWs to support their families; 40% live in a low-income household and 43% rely on public assistance.[51]

The 2026-2027 state budget, enacted July 12, 2026, includes the first significant increase to Medicaid home health nursing visit reimbursement rates in over two decades. As of this report's publication, the Pennsylvania Department of Human Services (DHS) has not yet published an updated fee schedule. Previously, DHS projected that it would take an $809 million increase to raise all direct care agency workers' wages to $14.58 per hour.[52]

Further, as 85% of homecare workers are women, 63% are people of color, 31% are immigrants, and over half have completed no formal education beyond high school, the wage and earning trends reflect and perpetuate the racial and gender inequities already facing these workers.[53]

Even if DCWs were appropriately compensated for their work, problems in accessing and affording this care would persist due to the long-running shortfall in LTC financing. In Pennsylvania, the monthly cost of a home health aide is $4,957 and, with limited options for consumers to cover these costs, Medicaid has become the primary payer for HCBS in Pennsylvania. Today, 117,000 Pennsylvanians receive HCBS via the Medicaid Community HealthChoices Waiver.[54]

Although this report will focus on the use of informal respite care services that are *not* provided by paid DCWs, their essential role in the caregiving system cannot be ignored. Unfortunately, the historically insufficient investment in this workforce has and will continue to strain the critical relationship between DCWs and family caregivers.

> *"The direct care workforce has too often been treated as an afterthought while healthcare priorities compete for funding. But every dollar invested in direct care workers pays dividends in the care, independence and quality of life of older Pennsylvanians. Strengthening this workforce is essential to meeting the needs of our aging population."*
>
> *— Rep. Dan Frankel, Majority Chairman of the House Health Committee in the Pennsylvania House of Representatives, and Co-Chair, IOP HHS Committee*



State of Respite Care in Pennsylvania



Millions of family caregivers providing untrained, unpaid care to their loved ones are in need of a range of supports that remain out of reach due to barriers at the federal, state, and local levels. One such support, and a focus of the IOP HHS Policy Committee's work, is respite care.

While respite care can be defined in a number of ways, it is best understood as planned or emergency care provided to a child or adult with special health needs in order to provide temporary relief to the unpaid family caregiver of that child or adult.[55] This type of support typically falls into one of two categories: formal and informal.

Formal respite care services are those provided by a paid professional and usually offered on a sliding fee schedule or funded through a combination of family fees, state and federal funding, including Medicaid waivers, and/or private insurance.[56] Examples of formal respite care include adult day centers or sitter-companion services administered by a service organization or specialized agency.

Informal respite care, on the other hand, is a temporary break for family caregivers provided by unpaid family members, friends, neighbors, and/or unrelated volunteers. Informal respite care includes a broad range of support, from a congregant at your local church spending time with your older relative while you run errands all the way to a nursing student at the local college dedicating several hours a week to relieving you of caregiving duties.

Like paid and unpaid caregivers, both forms of respite care are equally valuable and desperately needed. The IOP HHS Committee assessed impact and shorter term feasibility, and based on federal trends and Medicaid uncertainty, it concluded this report should focus on informal respite care networks that are not dependent upon federal funding, Medicaid eligibility, and the direct care workforce. In doing so, the committee was able to produce a range of viable strategies for increasing access to respite care for the greatest number of Pennsylvanians.

Implications of Federal Policy Shifts

Although this report does not focus on formal respite care programs that are funded and administered through Medicaid waivers, it's important to note that they have long been a vehicle for respite care. By providing access to benefits like adult day centers where Medicaid-enrolled family members are cared for by trained professionals, waivers indirectly offer family caregivers a break from their regular caregiving duties. As of this writing, however, there is nationwide uncertainty as to the future of waiver eligibility and service provision as a result of recent changes to Medicaid spending priorities at the federal level. The 2025 budget reconciliation law, H.R.1, significantly alters Medicaid financing, reducing federal spending by $911 billion over 10 years. States, already managing pinched budgets, may face tough financial decisions, which have traditionally resulted in cutting optional Medicaid services, such as HCBS.[57] Although it is too early to tell the law's full impact, recent administrative changes, like the restructuring of the Administration for Community Living (ACL) announced in 2025, will likely affect the long-term care ecosystem.[58] While these specific changes are beyond the scope of this report, it's important to note that reductions in overall Medicaid spending, and restrictions on how that funding may be recouped, will require states to consider strategies to reduce the costs of administering their state Medicaid.

State strategies to mitigate reductions in federal Medicaid funding include: raising taxes, limiting coverage, and reducing or eliminating benefits that are not explicitly required by federal law — including HCBS. It's for this reason that the committee decided to focus attention on respite care programs that would not be subject to fluctuations in overall Medicaid spending.

Access to respite not only may improve families' wellbeing, but as hospitalization and institutional care costs often fall upon Medicaid, state budgets are likely to benefit from the respite care availability.

The Impact of Respite Care

As a key component of family support and home- and community-based services, respite care can strengthen family systems while protecting the health and well-being of both caregivers and care recipients through a variety of benefits:

- **For caregivers of older adults**[59]
  - Decrease in self-reported burden over time
  - Reduced chance of neglect and abuse
  - Reduced nursing home entry
  - Fewer hospital admissions for acute medical care
  - Positive effects on caregiver health, motivation, fatigue, and psychological adjustment

- **For caregivers of children and adults with disabilities**[60]
  - Improved family stability
  - Reduced chance of abuse
  - Reduced out-of-home placements
  - Reduced out-of-pocket costs
  - Reduced stress
  - Improved marital quality

Respite is often cited by family caregivers as the most desired and requested service,[61] but it is incredibly underutilized: **86%** of family caregivers of adults and **75%** of carers of children with special health needs **have unmet needs for both formal and informal respite.**[62]

Moreover, respite has been shown to sustain caregivers' ability to continue caring for their loved ones over time, and can aid in delaying or avoiding altogether placement in institutional care. More research is needed, but available evidence shows respite may reduce future costs, such as hospitalization and institutionalization, as caregivers can better manage care and address concerns sooner.[63]

Types of Respite

In-Home Models

- **Home-Based Services**
  - Typically coordinated by a public health nursing agency, social service department, volunteer association, nonprofit organization, or private home care agency.
  - A trained and usually licensed agency employee is available to come into the home to offer respite.
- **Sitter-Companion Services**
  - May be provided by individuals trained in caring for children or adults with special needs.
- **Self-Directed Respite**
  - The person providing respite care may be a family member, friend, neighbor, or someone on a DCW or respite registry who is designated by the caregiver as the respite provider.
  - Providers may be paid or unpaid; if paid, typically through a voucher program[64].

Out-of-Home Models

- **Family Care Homes**
  - Respite is offered in the provider's home that is often licensed under state regulations.
- **Respite Center**
  - Respite programs that contract with existing day care centers that may or may not be licensed by the state.
- **Foster or Group Homes**
  - Short-term relief for caregivers and foster parents, provided in a safe, supervised environment.
- **Crisis Nurseries**
  - Free, voluntary, emergency child care for families managing unexpected crises.
- **Residential Facilities**
  - Some long-term residential facilities, particularly those serving individuals with developmental disabilities, have a specified number of beds set aside for short-term respite.
- **Parent/Family Caregiver Cooperative**
  - Often developed in rural or remote areas where traditional respite services are very limited.
  - Families of children with special health needs develop an informal association and "trade" respite services with each other at no cost.
- **Respitality**
  - New, innovative partnership between private sector hotels and respite agencies.
- **Hospital-Based**
  - Short-term inpatient care for medically-complex individuals.
- **Camps**
  - Camp-based temporary supervision for individuals with special needs.
- **Adult Day Services**
  - Have been providing a form of respite for caregivers for decades.
  - Typically offer health services, therapeutic services, and social activities.

Paying for Respite

Medicaid Waivers

As the largest source of funding for medical and health-related services for low-income residents, Medicaid often pays for HCBS through the state Medical Assistance plan as well as through Medicaid waivers that offer services as a lower-cost alternative to treatment in a medical or long-term care facility. These waivers, however, each have strict eligibility criteria and the services offered depend on the availability of direct care workers.[65]

- PA Adult Autism Waiver
- PA Consolidated Waiver
- PA Home and Community Based Care Waiver for Individuals Aged 60 and Over (Aging Waiver)
- PA Community HealthChoices Waiver
- PA Independence Waiver
- PA OBRA Waiver
- PA Community Living Waiver

> *"The profession is not looked at as a high-status profession, despite the fact that virtually every single family probably has to go through this at some point in their life."*
>
> *— Disability Policy Director, U.S. Senate*

Although these waivers have greatly increased both the array of services offered and the populations served, waitlists for eligible individuals have always been an issue in Pennsylvania as the Office of Developmental Programs (ODP) within the PA Department of Human Services (DHS) struggles with insufficient waiver capacity.[66]



Formal Respite Care

The IOP HHS Policy Committee decided that a focus on informal respite care networks would yield the most impactful results in the immediate term. Understanding the publicly funded formal system that provides professional respite to family caregivers is critical to recognizing the challenges families face in accessing this support. For that reason, this section will outline the various formal programs, and their corresponding funding mechanisms, below.[67]

Federal Programs and Funding:

- **Medicare**
  - Participants may receive respite care as part of Medicare's hospice benefit as well as through some Medicare Advantage plans that offer additional services to enrollees via supplemental benefits.
  - Only a minority of Medicare Advantage plans are providing respite-related services.
- **Medicaid**
  - Defined as intermittent or regularly scheduled medical care and/or supervision of the participant, Medicaid has traditionally offered many options for respite services, both in-home and community-based, through various waivers of traditional Medicaid rules.
    - 1915 (c) HCBS waivers
    - 1915 (b) managed care waivers
    - 1115 research and demonstration project waivers
  - Respite can also be offered through other Medicaid waiver services such as companion services, personal care, attendant care, medical day care, and adult day care.
- **Veterans Programs**
  - The federal Department of Veterans Affairs (VA) has traditionally offered direct services, budgets, and cash benefits that family caregivers can use for respite when they look after a veteran with disabilities or are the surviving spouse of a veteran.
- **Other federal programs**
  - The Lifespan Respite Care Program, administered federally by the Administration for Community Living (ACL), provides federal funds to eligible grantee states to coordinate, expand, and improve community-based respite services. Pennsylvania is no longer a grantee of this program.
  - The National Family Caregiver Support Program (NFCSP), administered by ACL, provides information, counseling, support groups, training, and respite care to family caregivers of ages 60 and older, and grandparents raising children.
- **AmeriCorps Senior Companion Program**
  - Recruits adults ages 55 and older to serve as companions to seniors and individuals with disabilities.

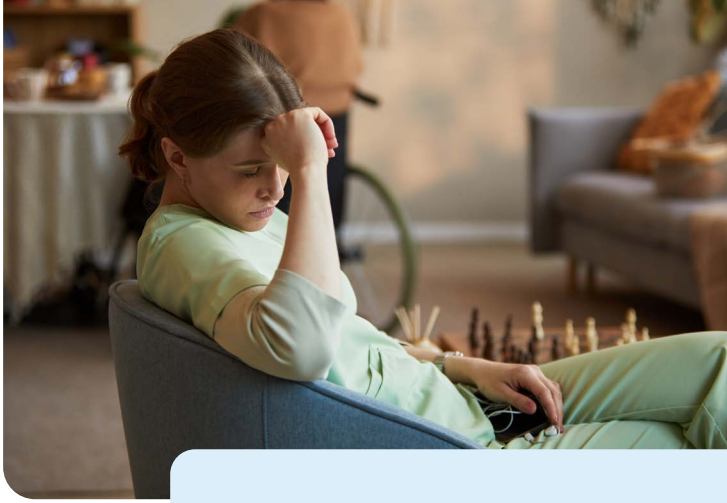
Pennsylvania Programs and Funding:

- **Pennsylvania Caregiver Support Program**
  - Administered by the Department of Aging.
  - Income-based eligibility.
- **Office of Developmental Programs**
  - Administered by the Department of Human Services, for individuals with intellectual disabilities who have respite included in their care plan.[68]
- **Bureau of Autism Services**
  - The Pennsylvania Bureau of Autism Services (BAS), administered by the Department of Human Services, funds respite care through the Adult Autism Waiver and the Adult Community Autism Program
- **Office of Child Development and Early Learning[69]**
  - The Office of Child Development and Early Learning (OCDEL) administers Pennsylvania's Early Intervention (EI) program, which provides supports to infants and toddlers. EI service coordinators connect parents of eligible toddlers with special needs to county-funded respite care programs.

Barriers to Formal Respite Care

In addition to the general costs of family caregiving outlined in the previous section, there are a variety of obstacles that hinder family caregivers' ability to access respite care even when they are aware of the service. These include:

- Reluctance to use respite or to self-identify as a caregiver
- Limited federal and state fiscal resources
- Out-of-pocket cost
- Shortage of qualified providers
- Limited options or appropriate programs
- Restrictive eligibility
- Difficulty navigating complex and fragmented administrative system



> *"Two of the issues that respite faces are nobody knows what the heck it is...and then that language doesn't actually resonate with the general public in any kind of meaningful way."*
>
> *— Beth Mulvaney, Direct Practice Chair and Clinical Assistant Professor, University of Pittsburgh School of Social Work*

In Pennsylvania specifically, these barriers are exacerbated by other factors related to Medicaid, operational capacity, and overall LTSS infrastructure. For example, there is no presumptive eligibility for Medicaid-funded programs in Pennsylvania, which makes emergency placement of a loved one in crisis extremely difficult.

Another obstacle to a more accessible respite care system in Pennsylvania is the lack of a single authority administering funds and monitoring local programs.

While the commonwealth was a Lifespan Respite Program grantee in the past, it has not been for several years. This isn't to say that there is no funding for respite programs but that there is a lack of a centralized effort to coordinate the respite system. The administration and tracking of formal respite care programs primarily occurs at the county level; programs targeting caregivers of adults typically operate in coordination with local Area Agencies on Aging while those targeting caregivers of disabled individuals operate through a variety of agencies and institutions that receive funding through a county authority.

Caregivers of individuals with autism or intellectual and developmental disabilities must navigate an even more fragmented landscape. These families must arrange for the care recipient's primary care physician to fax a referral to their insurance provider, which then decides the amount of care needed. The families must then locate respite providers on their own.[70]

Even in counties with robust human services departments, such as Allegheny County, the cost and coordination of formal respite programs funded with public dollars continue to have a negative impact on utilization by family members.

Past Efforts

The first effort to create a statewide plan to promote respite sustainability in Pennsylvania dates back to 1999 and preceded any respite legislation at the federal level. This effort eventually led to the formation of the PA Respite Coalition which, in partnership with the Family Support Advisory Council and the Institute on Disabilities at Temple University, held two respite summits in 2007 and 2009. The purpose of the summits was to address the Lifespan Respite legislation and prepare the commonwealth to create a system of sustainable respite across age and disability.

PA Respite Coalition 2007 & 2009 Recommendations and Strategies

These summits produced a variety of recommendations for improving our respite care system, as well as strategies to achieve these recommendations, including:

- Availability of emergency vouchers
- Regional respite offices
- Statewide advisory group that is inclusive of family members
- Create a 'map of need'
- Identify at least one or two colleges/universities willing to connect coursework to respite provision for college credit

Community Roundtable Recommendations, 2013-14

Two community roundtables were later conducted in September 2013 and April 2014 in the Southwest and Northwest region of Pennsylvania. These roundtables produced both short- and long-term recommendations that were never implemented, and did not result in substantive changes at the state or local levels.

Short term

- Specific disability should not be a prerequisite to services
- Help people understand what respite care is
- Inform legislators of respite care's value
- The Alliance for Community Respite Care (ACRC) in Allegheny County should be expanded statewide

Long term

- Reimbursement programs
- Organized statewide effort
- Legislative initiative to study respite care
- Toolkits to train volunteers in the community
- College and student volunteer groups[71]

> *"Respite has a lot of promise... but there are still design flaws and some of those design flaws are directly related to funding reimbursement."*
>
> *The role of respite has not been, from my point of view, as robust as it could have been."*
>
> *— Beth Mulvaney, Direct Practice Chair and Clinical Assistant Professor, University of Pittsburgh School of Social Work*

While the original statewide infrastructure collaborative dissolved, one of the founding partners of the now-defunct initiative remains active in Southwestern Pennsylvania. The Allegheny County Respite Care Alliance, founded in 1997, and now known as the Alliance for Community Respite Care of CLASS (Community Living and Support Services), remains a valuable resource to the respite community in Southwestern Pennsylvania and offers the following services to caregiving families:[72]

- Assistance in finding quality respite care through a single point of contact
- Data collection and information gathering
- Documentation of local respite needs and available services

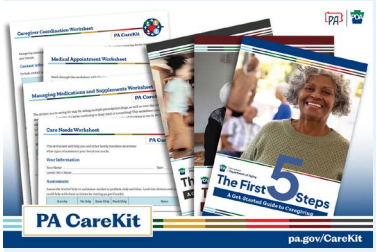
Recent Progress



In 2023, the AARP released their updated LTSS Scorecard that ranked Pennsylvania 34th in the nation for affordability and access to LTSS and 46th for support for family caregivers.[73] While these rankings expose Pennsylvania's system as inadequate by several metrics, there has been a concerted effort to improve ways in which the commonwealth supports its caregivers.

In June 2025, the Pennsylvania Department of Aging launched the PA CareKit, an online tool to support caregivers by providing resources for training, access to respite services, and personalized tools that can assist families caring for older adults and disabled individuals. The result of the implementation of Aging Our Way, Governor Josh Shapiro's 10-year plan to improve the infrastructure of aging services, this site offers a variety of tools that can help families locate respite programs in their county, learn how to support their own health and well-being, and access critical services for their loved ones.

PA CareKit is an online tool that supports caregivers with training resources, respite access, and personalized tools for caring for older adults and individuals with disabilities.



The **GUIDE Model** launched in 2024 with 100 health providers nationwide, and in 2025 grew to include nearly 400 programs.

In July 2025, the Guiding an Improved Dementia Experience, or GUIDE Model expanded to include several organizations in Pennsylvania. The federal program, an 8-year study conducted by the Centers for Medicare & Medicaid Services, or CMS, launched in 2024 with 100 health providers nationwide, and in 2025 grew to include nearly 400 programs.[74] This voluntary, nationwide model measures the impact of providing comprehensive supports for people with dementia and their caregivers. The model, funded by Medicare, addresses multiple facets of caregiving, including medication management, coordination of care, caregiver education and support, help with ADLs, 24/7 access to a support line, and especially relevant to the focus of this report, respite care. This last component covers respite services up to $2,500 annually,[75] which generally covers about 70 hours of respite per year.[76]

Unlike other models discussed in this report, the participants are providers, not patients, and the model is solely focused on high needs Alzheimer's and dementia patients. Despite these restrictions, the launch of the model signifies the first time the federal government has acknowledged the importance of caring for the caregiver.[77] It is important to note, however, that even though innovative new programs such as the GUIDE model are offering money to cover respite services, the current fragmentation and lack of infrastructure among respite providers makes finding care difficult, even if money is available.[78]

Informal Respite Care

The previous section of this report detailed the system of formal respite care options, its related funding mechanisms, and the barriers to its use by family caregivers. This section will outline the second model of respite care — the collection of informal networks that provide volunteer support to family caregivers seeking a relief from their caregiving duties.

The IOP HHS Policy Committee's goals were ambitious and reflected a desire to develop a set of strategies that could improve the entire system at the state, local, and community levels. As this work progressed, significant changes regarding Medicaid eligibility and human services funding at the federal level prompted the committee and the IOP to take a closer look at the range of programs that do not rely on government funding.

> This focus has the added benefit of including the population of people colloquially referred to as "the missing middle," the family caregivers for whom Medicaid-funded formal respite programs are unavailable due to issues like eligibility requirements and DCW shortages.

Unsurprisingly, the data available for informal respite models is limited compared to that of the formal models. As such, the IOP utilized research, analysis, and input from outside experts and stakeholders to inform this section of the report which will provide background information on volunteer- and faith-based respite care programs, as well as several examples of successful models found in both Pennsylvania and other states.

Faith-Based Respite Care



Historically, faith communities in the United States have played a significant role in shaping and supporting their larger community whether through public events, education, or charitable activities. Today, many faith communities seek to serve both the spiritual needs of their congregations and the many social needs of their local community. In many service areas, particularly those in rural Pennsylvania counties, faith communities may be the main source of support for vulnerable residents that are either unwilling or unable to utilize government-funded services. As such, they possess many resources, connections, and characteristics that can prove valuable to support respite care initiatives, including:

- Desire to contribute to the local community
- Culture of volunteerism
- Sustainability
- Facilities
- Non-profit status for philanthropy

Utilizing faith communities to provide and access respite care has nonmaterial benefits as well, including an increased sense of belonging for families of disabled individuals, new skills for caregivers and volunteers, and an increased awareness of the respite needs of local families. Faith-based programs operate in a multitude of ways and reach a diverse array of people who may or may not be a part of that faith or ministry. Typically, however, these programs are provided at little to no cost and operate as an out-of-home model of respite.[79]

Bethel Life – Loving Hands (Greenville, PA)

Loving HANDS at Bethel Life Worship Center is a "Special Needs Ministry" that provides respite once a month for three hours for families who have children with physical, intellectual, or behavioral disabilities. Provided at no cost, attending children are paired up with a trained volunteer for the evening to enjoy a variety of activities including a bounce house, ball pit, video game stations, and snacks. Bethel Life also offers *Loving HANDS Prime* for families with similar children over the age of 18 that would enjoy a more adult-like atmosphere with music, dancing, games, karaoke, crafts, and more.

In addition to this on-site respite option, Bethel Life offers *Connect*, a faith-based church service for disabled individuals who must be accompanied by an adult or other caregiver.[80]

Volunteer-Based Respite Care

> *"Volunteer-based respite care is freely given, but it is not free."*
>
> *— MaryJo Caruso, Former Director of CareBreak Respite Care Program, Sewickely, PA*

The use of volunteers to provide respite for family caregivers has become an increasingly common way to increase accessibility, curtail costs, improve affordability, and expand the social networks of these families. Volunteer programs are essential to families who may be ineligible for publicly-funded services and cannot afford out-of-pocket costs, who live in geographically isolated areas, or who struggle to find help due to a shortage of paid providers. Volunteers can also be an asset to the service provider as they are unpaid and allow limited resources to be stretched to cover more families. While volunteer respite carries some costs and may not be feasible for every organization, it can serve as a lifeline to family caregivers who are in crisis or have run out of options.[81]

As outlined earlier in this report, respite care can include a broad array of services that occur in the home, facilities, or any number of other settings, all of which can utilize volunteers that are adequately trained, supported, and supervised. Not limited to offering direct services, volunteers can also provide crucial organizational support through administrative duties, fundraising, transportation, and promoting public awareness.

The exact deployment of volunteers varies greatly across programs and each carries varying costs, time requirements, and eligibility. Two examples of these programs located in Pennsylvania can be found below.

Take Five Project and the CareBreak Model

In 2014, the U.S. Department of Health and Human Services opened an RFA through the Maternal and Child Health Services Title V Block Grant for the creation or expansion of volunteer respite in 25 communities called TakeFIVE. In Southwestern Pennsylvania, TakeFIVE was deployed as the "CareBreak Model" by the Watson Institute.

This project trained 20+ faith-based and community organizations such as YMCAs, JCCs, and churches to run volunteer respite programs for families of children with special health needs. Awarded $202,000 over five years, the initiative was designed to help increase the availability of respite services through access to trained volunteers, as well as offer training, support, and limited funding to develop or expand volunteer

(continued on next page)

Take Five Project and the CareBreak Model *(continued)*

respite programs through immediate and ongoing training and technical assistance. Volunteers were required to be over 18 years of age and to commit six months to the program, although the majority of them stayed on for three to five years.[82]

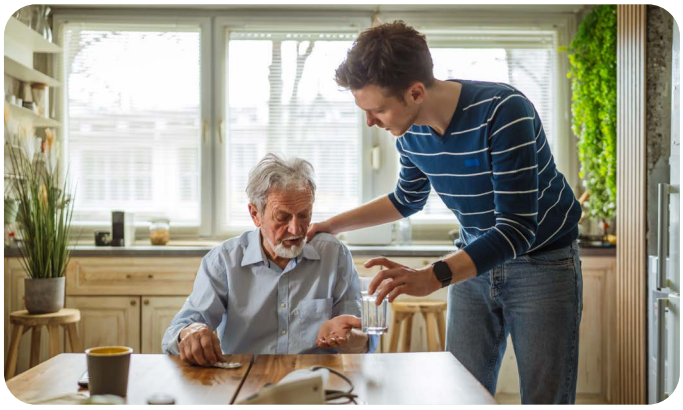
Both the TakeFIVE program and CareBreak Model monitored and evaluated their programming and boast positive outcomes.[83] TakeFIVE reported 720,000 hours volunteered on behalf of Pennsylvania families of children with special needs; this time, measured over a 2.5 year period, was valued at $10.5 million (based on the Pennsylvania Department of Labor & Industry hourly rate for home health aides).[84] The CareBreak Model measured caregivers' stress levels via pre-service and post-service surveys, and observed a statistically significant reduction in stress levels post-service.[85]

While the federal funding for the TakeFive initiative ended after five years and the project was officially dissolved, several participating organizations were able to sustain their volunteer programs that are still in operation to this day.

Time Out (Temple University)

Established in 1986 by the Intergenerational Center at Temple University with funding from the AARP Foundation, the United Way, and other national and local funders, Time Out is an in-home support program in which college students provide high quality, low-cost respite services to families caring for vulnerable older adults. The program seeks to reduce caregiver stress and the social isolation commonly experienced by caregivers and their relatives and offers eligible college students valuable experience and connection to the older residents in their community.[86]

Staffed by a full-time Director and part-time Coordinator serving approximately 100 families per year, the program matches students with families following eight hours of training, recommendations, and background checks. While the families pay students $8/hour directly, many Temple students receive Federal Work-Study grants that can cover the cost of respite for the family for whom the student works. All students are covered under the university's liability insurance and they typically visit families two to three times a week, providing six to eight hours of respite services.



Recommended Strategies



Given the enormity of this policy issue and the predicted disruptions to Medicaid recipients and LTSS, the IOP Health and Human Services Policy Committee focused on policy options that support family caregivers and their access to respite care without relying on federal funding or Medicaid-based programs.

With feasibility at the forefront, the committee's recommendations span a range of viable strategies that would require action at the state, county, or local levels and both with and without additional funding. The recommendations are structured to provide a brief overview of the strategy, the policy levers required to enact change and finally, examples of implementation from other states. In short, the committee's recommendations fall into one of the following categories:

1. Legislative Action
2. Employer Engagement and Workplace Support
3. Outreach and Awareness
4. Research, Data Collection, and Coordination
5. Toolkits
6. Innovative Settings and Providers

1. Legislative Action

The committee explored the feasibility of several policy actions that would require legislative action from the Pennsylvania General Assembly.

Caregiver Tax Credits

State tax credits for full-time unpaid caregivers and out-of-pocket costs can be one way to offset a portion of lost income and benefits caused by family caregiving responsibilities. While federal law offers working family members a child and dependent care tax credit for a portion of the cost of caregiving, nonworking, full-time caregivers are ineligible.[87] Statewide legislation would relieve some of the financial burden on Pennsylvania caregivers who do not work. This policy intervention enjoys broad bipartisan support, with 82% of registered voters (87% of Democrats and 79% of Republicans), supporting tax credits to support family caregivers, according to a recent poll.[88]

82% of registered voters support tax credits to support family caregivers

EXAMPLE: *Caregiver Tax Credit Act* (Nebraska)

- Passed in 2024, Nebraska's Caregiver Tax Credit Act is the second in the nation to offer a non-refundable tax credit for out-of-pocket costs incurred by the unpaid family caregiver for a limited set of services.
- Allowable expenses must be directly related to assisting the caregiver in providing care for their family member.
- The credit is capped at $2,000 per year for most participants.

Self-Directed Respite Vouchers

Self-directed respite vouchers allow family caregivers to hire a respite worker of their choosing, including other family members, friends, or neighbors who already know the person receiving care. While traditional service delivery models typically invest decision-making powers in professional program employees or service providers, a self-directed voucher system transfers much of this authority to the caregiver. Voucher systems can also be a more cost-effective service model as the family caregiver takes on more responsibilities which can lower administrative costs and reduce institutional placements.



The benefits of these systems have been found to be especially pronounced in rural areas experiencing workforce and service shortages.[89]

EXAMPLE: *"Respite RX" Self-Directed Respite Pilot Program* (Nevada)[90]

- With the primary goal to remove as many internal and external barriers to respite services as possible, Nevada designed a self-directed respite option targeted to fill certain gaps in the social service delivery system, specifically in rural areas and for populations caring for individuals aged 18-59.
- Eligible caregivers included those unable to qualify for other respite programs due to limited eligibility criteria, waitlists, or program reach that did not deliver care after-hours, weekends, or overnight.
- Created in 2018, 60 families were given a full year to utilize their budget of $308 per month, or $3,696 for the year.
  - > The program recommended 2-4 hours of respite per week though it was ultimately up to the participants.
  - > Each caregiver received the same monthly allotment of funding which covered the cost of the respite service and any employer-paid payroll taxes under their spending plan.

2. Employer Engagement and Workplace Support

It is estimated that U.S. businesses lose between $17.1 and $33 billion annually because of lost productivity of family caregivers that occurs in the form of absenteeism, reduced hours, and replacement of staff who have left the workplace due to caregiving duties.[91]

Recognizing the significant role employer benefits and workplace flexibility can have on working family caregivers, and that protecting these caregivers from impoverishment delays the use of state programs, the committee recommended exploring various ways to engage the business community and considering state-level action to support employed caregivers. A recent poll indicates overwhelming bipartisan support for employer incentives to support caregivers, with 80% supporting expanded federal tax credits and incentives to help employers with the costs of providing caregiving benefits to employees (87% of Democrats and 75% of Republicans polled).[92]

80%
of voters support expanded federal tax credits and incentives to help employers with the costs of providing caregiving benefits to employees

Expanded leave benefits

- The federal Family and Medical Leave Act (FMLA) allows eligible employees of covered employers to take limited unpaid, job-protected leave for family and medical reasons.
  - Only 56% of employees are eligible for FMLA.
  - Does not apply to all types of family members or chosen family, meaning loved ones who play significant family roles regardless of biological relationships or legal recognition.
- Several states have enhanced FMLA by:
  - Covering workers in businesses with fewer than 50 employees.
  - Expanding the definition of "family member" to include extended family, in-laws, stepfamily, and family of choice.
  - Decreasing the time an employee must work before becoming eligible.[93]

Protections against workplace discrimination based on family caregiving requirements

- Delaware and the District of Columbia have enacted anti-discrimination laws that specifically define and protect "family" and "family responsibilities."[94]

Employer-sponsored respite care benefits

- Colorado has explored ways to encourage employers to fund respite services directly or include them in their health benefit plans through a state employer tax credit.[95]

> *"I was proud to take part in this report and look forward to analyzing the recommendations as we address the real need for respite care for our family caregivers."*
>
> *— Rep. Jim Struzzi, Minority Chairman of the House Appropriations Committee in the Pennsylvania House of Representatives, and Member, IOP HHS Committee*



3. Outreach and Awareness

One problem frequently cited by family caregivers, researchers, and service providers is the lack of general awareness surrounding respite care services.

While Pennsylvania has certainly made significant progress in creating a one-stop-shop resource directory through the PA CareKit, it can only help those who are willing to identify as caregivers or know that respite is something that both exists and can benefit them. All committee members recognized this issue as a significant barrier to utilization of respite services and recommended low-cost ways to improve the salience of respite among Pennsylvania residents.

EXAMPLE: *"Are You a Caregiver?"* Campaign (Delaware)

- Delaware Division of Services for Aging and Adults with Physical Disabilities launched a marketing campaign to assist caregivers in self-identification by helping them identify the everyday tasks that they might do as a caregiver and how they can access support.[96]
- Local radio, tv, print, and Facebook ads provided a description of a caregiver "task" connected with a phone number to the Aging and Disability Resource Center to direct caregivers to information and referral services.

EXAMPLE: *Medical Community Initiative* (South Carolina)

- South Carolina's Respite Coalition partnered with a local university to develop informational referral cards and posters to educate the medical community about respite, offer guidance in assessing the need for respite among their patients, and aid them in directing family caregivers to respite resources.[97]

4. Research, Data Collection, and Coordination

Despite the abundance of research pertaining to family caregiving and respite care on a national level, very little has been produced regarding demographics, service availability, and respite utilization in Pennsylvania at the commonwealth level. There has not been a statewide initiative to gather a broader understanding of our family caregivers and their respite needs.

Entities like the University of Pittsburgh's Center for Caregiving Research, Education and Policy have been instrumental in producing invaluable data at the Allegheny County level. A statewide data collection initiative would provide a comprehensive picture and assure both urban and rural needs are identified and met.

Several committee members, particularly the elected officials, expressed frustration with the information silo that persists across municipalities, counties, and service areas as it hinders their ability to develop a coordinated plan.

This dearth of information is not necessarily the result of state inaction, however, as family caregivers are not included in Medicaid claims or electronic health records and many have no contact with the Medicaid or public benefit system at all.

The unsurprising lack of concrete data regarding informal respite care networks was a particularly significant challenge as the committee aimed to bolster the infrastructure necessary to increase access and utilization of these cost-effective, community-based programs. As the issue of data collection and cross-sector coordination is not unique to Pennsylvania, the committee recommends referring to initiatives in other states in building a plan to address these knowledge gaps here.

EXAMPLE: Washington State

- Washington collects data from all counties, including the number of initial caregiver contacts, referral sources, respite vouchers applied for and received, and demographic data of caregivers and care recipients to track the efficacy and impact of their various respite care efforts.[98]

EXAMPLE: Massachusetts

- Massachusetts' Lifespan Respite grantee is working with all state agencies that fund or provide respite services in the state in order to reconcile respite definitions that are tied to categorical funding rules and to identify common data elements that will allow agencies to capture demographic, service, and cost data across agencies and programs.[99]

EXAMPLE: Minnesota

- In 2016, the Minnesota Board on Aging contracted with the Wilder Foundation to better understand how the state delivered National Family Caregiver Support Program (NFCSP) services and investigate opportunities for improvement. This collaborative effort produced research that describes what services are available to caregivers, which ones were being used and in what patterns, and opportunities to adapt services that could be reflected in Minnesota's state plan. Area Agencies on Aging, key experts, and stakeholders were interviewed to collect pertinent caregiving information.[100]

5. Expanding Informal Respite Networks through Technical Assistance to Community-Based Organizations

A lack of knowledge regarding respite care networks was frequently cited throughout the research and stakeholder interviews conducted by the IOP. From the beginning, the committee stressed the importance of creating material tools that would assist providers, potential partners, and the public generally in establishing new respite programs or enhancing existing ones.

Through committee discussions, it became clear that the design and dissemination of a toolkit would be the most viable mechanism to increase local organizations' ability to become respite care providers. As the examples below demonstrate, respite toolkits span a variety of goals and audiences and many have been guided by assistance from the Lifespan Respite Program.

EXAMPLE: *Volunteer Respite Manual* (ARCH Respite)

- Designed to help national, state, and community-based programs and faith-based initiatives assess needs, plan, and implement volunteer respite programs.[101]

EXAMPLE: *Faith Community Toolkit* (North Carolina Respite Care Coalition)

- Intended for faith-based organizations and ministries that have expressed a need for, or interest in, a respite care network within their congregation and community.[102]

EXAMPLE: *Providing Respite Toolkit* (New Jersey Department of Human Services, Division of Developmental Disabilities, and Division of Aging)

- Designed for local organizations and provider agencies, this toolkit offers a background in respite care, demonstrates the need for respite services in New Jersey communities, and provides a step-by-step instructional guide on how to become a formal respite care service provider.[103]

6. Innovative Settings and Providers

As this report has outlined, the current capacity for traditional, formal respite provided by paid providers is unable to keep up with the demand from family caregivers and their families.

In addition to the policy and resource recommendations detailed earlier in this section, the committee looked at several innovative informal respite care options that could be established without significant legislative or regulatory changes. As the following examples demonstrate, institutions of higher education can often be vital partners in recruiting and overseeing volunteer-based programs that offer curriculum enhancements to students while serving local families in campus facilities.

It is important to note, however, that much like the state toolkits and other initiatives highlighted in this section, these innovative strategies all received start-up funding and technical assistance from the Lifespan Respite Program. Though many have since contributed state funds to informal respite activities, an initial investment of funding and administrative guidance would be required to implement similar programs in the commonwealth.

EXAMPLE: *Nursing Student Respite Workforce Initiative* (Rhode Island Office of Healthy Aging)

- Following a Lifespan Respite Grant funding award in 2014, the Rhode Island Office of Healthy Aging implemented a workforce development initiative to match student nurses with low- to moderate-income families who have no access to subsidized respite care.
  - The initiative followed a statewide gap analysis that revealed an inadequate respite framework.
- Grant partners Rhode Island College School of Nursing and the University of Rhode Island College of Nursing chose to adapt the nursing respite component of their curriculum to their respective needs in a way that complemented current offerings.
- With administrative and matching support from the schools, this model provides free respite care with an increased supply of volunteer respite providers while offering hands-on experience for nursing students.[104]

EXAMPLE: *Claude Moore Precious Time* (James Madison University)

- Since 2005, the Precious Time program has deployed nursing and health and human services students to provide pediatric respite care as part of a supervised student learning experience.
- The program has supported 237 families, educated 3,038 students, and provided 39,508 student hours of free respite care.[105]

EXAMPLE: *Respite Breakrooms* (South Carolina Department of Aging and South Carolina Respite Coalition)

- One of the many faith-based respite care models, breakrooms offer a caregiving break at a physical site, staffed primarily by volunteers, where care recipients can participate in activities and socialize with others.
- The initial pilot program used a mini-grant process to work with six faith-based programs to develop these breakrooms and later create a How-To Guide to help other groups develop breakrooms in their communities.
- In South Carolina, breakrooms that provide a temporary respite break for less than four hours do not require licensing from the state.[106]

Launching New Voluntary University Models

A university-based volunteer respite care model can be developed using an evidence-informed, two-part framework: program development focused on model fidelity, and structured volunteer training grounded in evidence-based practices. The Take FIVE model, replicated from the CareBreak program and funded through Title V of the Maternal and Infant Child Health program in Pennsylvania, offers a proven template. Clarion University successfully implemented this approach by securing Title V funding and building a campus-based volunteer program, as did a quasi-university initiative in Saipan — both trained using the same curriculum. Universities interested in replication can partner with their state's Title V Children with Special Healthcare Needs program to pursue funding, then engage a trained implementer to deliver both the program development and volunteer training components, as Temple University's University Center for Excellence in Developmental Disabilities did when it contracted to bring this model to scale.[107]



Conclusion

This report is the culmination of a two-year effort to identify the myriad challenges facing family caregivers, understand how and why these challenges persist, and develop strategies to address them. Through research, stakeholder engagement, and much deliberation, the IOP Health & Human Services Committee determined that the respite care system in Pennsylvania had the greatest need for insight and innovation.

In the spirit of the IOP's collaborative problem-solving and policy work, the issue of respite care enjoys broad bipartisan support. Family caregiving, while rewarding, can be immensely challenging for caregivers, many of whom span broad socioeconomic backgrounds and comprise a growing proportion of middle-income families.

Utilizing respite to care for the caregivers can prevent burnout, sustain family members' ability to care for loved ones, and reduce or eliminate hospitalization and long-term institutional care. These outcomes not only benefit care recipients and their caregivers and families, but also caregivers' employers and the economy at large, as well as Medicaid and state budgets.

As feasibility and impact have been the committee's top priorities from the beginning, this report serves two primary purposes: (1) to increase public awareness of the reality of family caregiving and the need for respite care, and (2) to educate leaders and policymakers at the local, county, and state levels on the ways in which they can improve the accessibility and availability of respite care.

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