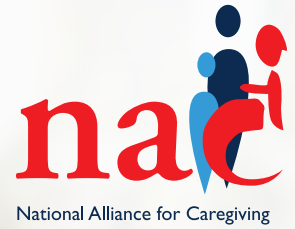




Social Innovations In Caregiving:  
**SPOTLIGHT ON MENTAL HEALTH**



National Alliance for Caregiving

OCTOBER 2023

# Caring for the Carers: **A Spotlight Brief on Supporting the Mental Health of Family Caregivers**

## EXECUTIVE SUMMARY

Family caregiving can be rewarding, fulfilling and a way to grow closer and spend quality time with a loved one. However, family caregivers can also find the role taxing, and it is taking a toll on their mental health. Sadly, caregivers often don't have the resources or tools to effectively identify their mental health needs or the ability to access needed support to navigate the issues that they are experiencing. Further, family caregivers are rarely included in national conversations about policy solutions that address their mental health. Due to increased conversations regarding mental health during the COVID-19 pandemic and a renewed focus on mental health policy by the federal government and other stakeholders, this is an opportune time for increased advocacy and the development of policies that examine the mental health needs of family caregivers. In light of these issues, the National Alliance for Caregiving (NAC) is pleased to present “**Caring for the Carers: A Spotlight Brief on Supporting the Mental Health of Family Caregivers.**”<sup>1</sup>

“  
It is mentally  
exhausting at times,  
especially when  
you feel like you  
are drowning with  
everything going on.  
– Caregiver

This Spotlight Brief strives to elevate the mental health of family caregivers, increase dialogue, and highlight policies that can help address the country's mental health crisis. Family caregivers, especially diverse caregivers, are resilient in the face of immense structural barriers, and continue to make large contributions to their families and communities. NAC hopes that the insights and recommendations provided here serve as a call to action to raise the alarm on this important issue as we seek to make caregiving more dignified, equitable, and sustainable.

As part of NAC's work to examine the mental health needs of family caregivers, NAC conducted a literature review and held a virtual convening of caregivers, advocates, and mental health experts to discuss the challenges and barriers that family caregivers face in addressing their mental health needs. This Spotlight Brief builds on the findings from the literature review, family caregiver engagement, and the insights shared during a virtual convening with subject matter experts.

Further, after synthesizing these insights, NAC identified four emerging policy areas that could aid in prioritizing the mental health of family caregivers: behavioral health equity, mental health parity, mental health professional workforce readiness and shortages, and adoption of whole health system approaches. In addition to these four areas, expanded research is presented as a critical cross-cutting recommendation.

Based on these areas and other insights learned during this process, NAC recommends the following:

- **Behavioral Health Equity:** Increase funding to support research and practice on the needs of all caregivers regardless of race/ethnicity, socioeconomic status, sexual orientation, language or geographical location and encourage the development of culturally-responsive training tools for health care professionals.
- **Mental Health Parity:** Expand mental health parity protections for family caregivers by expanding mental health parity protections in Medicare Advantage, Part D, to all Medicaid recipients, and to individuals with private health insurance.
- **Mental Health Professional Workforce Readiness and Shortages:** Reimburse providers at levels that will incentivize them to take the time to address the mental health needs of family caregivers and provide training and therapy to address caregivers' mental health needs. Support programs that will provide financial assistance to individuals desiring to enter the mental health field through scholarships and loan forgiveness programs and examine pathways to create a sustainable funding stream for community health workers.
- **Adoption of Whole Health System Approaches:** Increase funding for additional research on Whole Health System approaches, specifically, the use of mental health professionals in this model and the types of assessment, screening, and referral tools that could aid family caregiver mental health.

<sup>1</sup>This Spotlight Brief focuses on the mental health needs of family caregivers. For this reason, the term “mental health” will be used predominantly in this brief. The brief does contain the term “behavioral health” as well. Mental health refers to how an individual's psychological state affects their well-being while behavioral health centers on how a person's actions affect their well-being. Mental health is a component of behavioral health. For this reason, the term behavioral health is used as a title in the equity section of the brief as the discussion encompasses more than just mental health, but the overall system of care in this realm.



## The COVID-19 pandemic changed how both mental health and family caregiving are perceived and examined.

### INTRODUCTION

Our country is experiencing a shift – a mindset shift. A shift from the previous stigma surrounding mental health -- that was characterized by little to no public discussions -- towards a more open, welcoming, and honest dialogue on mental health needs, treatment, and access to services. This shift mirrors the growing visibility of family caregiving and the essential, yet under-supported, roles of family caregivers.

The COVID-19 pandemic changed how both mental health and family caregiving are perceived and examined. The pandemic was mentally and physically taxing, causing widespread anxiety and uncertainty about how the virus was spread and contracted,

the effects of social isolation, the loss of loved ones, and the loss of financial stability—all of which contributed to a decline in mental health. A Kaiser Family Foundation report noted that in the United States, four in 10 adults reported symptoms of a depressive disorder or anxiety during the pandemic.<sup>2</sup> This number is up from one in 10 adults reporting the same symptoms in early to mid-2019.

These are acute issues for America's 53 million unpaid family caregivers.<sup>3</sup> This growing community – and their mental health needs – are often overlooked in conversations and policymaking around mental health. Caregivers were disproportionately impacted by

the pandemic due to financial stress, increased worry about their care recipient's health, lack of access to respite care, increased social isolation, and worsening health due to skipping needed health care appointments.<sup>4</sup> During the pandemic:

- **Well-Being:** Over 70% of caregivers were concerned about their care recipient being infected with COVID-19.
- **Financial Concerns:** Almost 30% of caregivers struggled financially to provide care.
- **Respite Care:** Close to 60% of organizations that support unpaid caregivers cited a lack of respite care as a top concern of caregivers.

<sup>2</sup>Koma, W., True, S., Biniek, J.F., Cubanski, J., Orgera, K., & Garfield, R. (2020, October 9). One in four older adults report anxiety or depression amid the Covid-19 pandemic. KFF. <https://www.kff.org/medicare/issue-brief/one-in-four-older-adults-report-anxiety-or-depression-amid-the-covid-19-pandemic/>

<sup>3</sup>The National Alliance for Caregiving and AARP. (2020, May). Caregiving in the U.S. 2020. Retrieved July 8, 2023, from [https://www.caregiving.org/wpcontent/uploads/2020/06/AARP1316\\_RPT\\_CaregivingintheUS\\_WEB.pdf](https://www.caregiving.org/wpcontent/uploads/2020/06/AARP1316_RPT_CaregivingintheUS_WEB.pdf).

<sup>4</sup>NORC. Caregivers in America during Covid-19. <https://www.norc.org/content/dam/norc-org/pdfs/OACCaregiverInfographic.pdf>





## Snapshot of Caregivers' Mental Health<sup>8</sup>

- Four in 10 caregivers **experience high emotional strain.**
- **Emotional or mental health issues** are more often reported by those who care for someone 50 years of age or older; serve as a primary caregiver or partner; and care for someone with a long-term physical condition.
- Almost three quarters (**74%**) of caregivers **feel alone.**
- Levels of **emotional distress** by race:
  - Asian Americans (41.9%)
  - African Americans (30.5%)
  - Latinos (27.6%)
- Women report experiencing **higher stress** compared to men.



More than one in five people in the United States care for a family member, friend, or neighbor with a health care need or functional disability.<sup>5</sup> The average duration of caregiving is 4.5 years, with one-third of caregivers providing care for five years or longer.<sup>6</sup> More family caregivers are caring for multiple people (24 percent) and working while caregiving (61 percent). Increasing numbers of family caregivers are finding it difficult to coordinate care for their care recipient and four in 10 caregivers are in high-intensity care situations.<sup>7</sup> Needless to say, caregiving is becoming more prevalent, complex, intense, and inequitable.

### “Sadness, Exhausting, Burdened.”

This is how one caregiver described their experience. Now is the time to address the mental health needs of family caregivers before a new crisis unfolds. The goal of this Spotlight Brief is to expand the dialogue around mental health policy and practice change to

include and better address the needs of America's 53 million unpaid family caregivers. Due to the sheer number of caregivers in the United States and the critical role that they play in the lives of their care recipients, it is paramount that their mental health needs are understood and addressed.

### BACKGROUND AND KEY INSIGHTS

NAC is dedicated to building a more holistic and responsive healthcare system for caregivers. A truly responsive healthcare system is a system that serves the whole person – mind and body. A holistic system not only recognizes but also responds to the unique mental health challenges caregivers face in caring for those with acute and chronic illnesses, rare illnesses, and disability.

To advance this goal, NAC engaged in a multi-phase process to understand the current state of mental health practice and policy related to family caregiving.

“

Caregiving for my partner with Parkinson's has negatively affected my mental health. I feel helpless, alone, frustrated; and sometimes, I feel trapped. My stress level is much higher as I am the only income earner. I fear the cost of medical care in the future especially if I lose my job.”

– Caregiver

<sup>5</sup>The National Alliance for Caregiving and AARP. (2020, May). *Caregiving in the U.S. 2020*. Retrieved July 8, 2023, from [https://www.caregiving.org/wpcontent/uploads/2020/06/AARP1316\\_RPT\\_CaregivingintheUS\\_WEB.pdf](https://www.caregiving.org/wpcontent/uploads/2020/06/AARP1316_RPT_CaregivingintheUS_WEB.pdf).

<sup>6</sup>Ibid.

<sup>7</sup>Ibid.

<sup>8</sup>The National Alliance for Caregiving and AARP. (2020, May). *Caregiving in the U.S. 2020*. Retrieved July 8, 2023, from [https://www.caregiving.org/wpcontent/uploads/2020/06/AARP1316\\_RPT\\_CaregivingintheUS\\_WEB.pdf](https://www.caregiving.org/wpcontent/uploads/2020/06/AARP1316_RPT_CaregivingintheUS_WEB.pdf).

## NAC MENTAL HEALTH INITIATIVE

Subject Matter Expert Advisory Committee	Literature Review	Family Caregivers Listening Sessions	Virtual Expert Convening
NAC recruited an advisory committee of 10 experts in the family caregiving and mental health fields, including caregivers, health care providers, and social workers. The committee provided their insight and input on all aspects of the project and assisted in the development of the virtual mental health convening.	A literature review was conducted in two phases using the databases PubMed, Cochrane Database of Systematic Reviews, Google Scholar and DeepDyve. A total of 20 articles were found in order to provide an understanding on how family caregiver mental health is currently being studied and addressed through interventions.	From November 2022 to April 2023, nearly three dozen family caregivers participated in a digital engagement initiative that solicited their feelings, experiences, and impressions about their mental health. Engagement was made available in English, Spanish and Mandarin.	In May of 2023, NAC hosted a virtual convening with more than 40 subject matter experts and family caregivers to explore the challenges family caregivers face in addressing their mental health needs and how the mental well-being of family caregivers could be advanced through policy.

After analyzing and synthesizing the data generated throughout this process, NAC identified the following key insights:

### Key Insights

- **Behavioral Health Equity:** Family caregivers who identify with diverse and intersecting backgrounds, including race and ethnicity, LGBTQIA+ status, income, and geographic area (i.e., rural), are disproportionately provided with mental health supports. Racially diverse caregivers experience barriers to behavioral health services and care including access barriers; bias, discrimination, and negative experiences within the health care system; provider shortage due to the limited number of providers from diverse racial/ethnic backgrounds; and lack of culturally-competent providers to meet cultural, social, and language-related needs. Additionally, cultural norms may play a role in enforcing a sense of caregiving responsibility which can affect mental health. These structural obstacles and cultural factors can have an adverse effect on mental health by increasing caregiver anxiety and stress.
- **Family Caregiver Mental Health Research:** Additional peer-reviewed research on family caregiver mental health is needed to garner the attention and action of health care providers, social service providers, and policymakers. Currently, there is no consensus on the types of interventions that are beneficial to caregiver mental health. Increased research is needed to identify potentially useful interventions, particularly in the area of diverse caregivers, as well as opportunities to translate existing research and programming into policy and practice.
- **Mental Health Parity:** Even with legislation requiring mental health parity, achieving parity is still difficult. Many mental health providers are often out-of-network for many individuals' insurance plans and some providers don't accept insurance at all, making mental health treatment inaccessible and unaffordable.
- **Mental Health Professional Workforce Shortage:** There are a variety of professionals who provide mental health services. These individuals vary in their areas of expertise, training, and funding streams. Even with this array of providers, there is a current shortage of mental health professionals which negatively affects access to treatment.
- **Health Care Provider Readiness:** General practitioners are currently not receiving adequate training, financial incentives, and education on family caregiver issues to properly and timely address caregiver mental health needs. Providers don't know what questions to ask, where to refer patients, and may not be aware of available mental health supports. A more standardized approach to screening is needed which could aid in improving care navigation and support.
- **Adoption of Whole Health System Approaches.** The Whole Health System approach to health care is a comprehensive, integrated, and holistic approach that holds promise in addressing the overall needs of family caregivers. This model recognizes the importance of mental health and that mental health professionals are an integral part of the interprofessional care team which will allow them to assess and address caregiver mental health.

“

It's very difficult for caregivers and family members such as myself to talk to even a case manager, let alone a scared doctor. The scared doctors don't talk to the family member, and this creates even more distress for the patient. Scared doctors don't seem to understand or care.”

– Caregiver

These insights, against the backdrop of current public policy discussions and global health events, helped to serve as the basis for the policy opportunities that NAC has identified. Addressing family caregiver mental health is a matter that stands to affect all of us at some point. The following policy opportunities can serve as a roadmap to aid and ease this process.

## EMERGING POLICY OPPORTUNITIES

The wide-ranging effects of the global COVID-19 pandemic, including increased rates of depression and anxiety, have helped to make mental health a policy priority at the federal level. As a result, there are efforts to examine policies related to the utilization and availability of behavioral health services among Medicare beneficiaries by the Medicare Payment Advisory Commission. Additionally, the Centers for Medicare and Medicaid Services issued regulations that would strengthen network adequacy, which is a health plan's ability to provide reasonable access to in-network primary care and specialty physicians.

There are also efforts to expand behavioral health services by enlarging the network of essential community providers - providers who serve predominantly low-income, underserved individuals - to include substance use disorder treatment centers.<sup>9</sup> All of these policy efforts stand to positively affect family caregivers by increasing access to behavioral health services while providing current data on the availability, utilization, and quality of mental health services. This renewed focus on mental health provides policymakers and advocates with an opportunity to proactively work to make behavioral health care more accessible, affordable, and effective for family caregivers.

Based on the key insights generated by NAC's Virtual Expert Mental Health

Convening, four policy opportunities have been identified that could support expanded access to mental health services, identification of caregiver needs and supports, ways to bolster the mental health professional workforce, and methods to recognize and value the contributions of diverse caregivers.

All of society benefits when everyone has access to the same services, supports, and treatment opportunities that allow them to live healthy, fulfilling lives. Policies that advance equity, in all its forms, should be explored, examined, and supported.

## BEHAVIORAL HEALTH EQUITY

Behavioral health equity is defined as the "right of all individuals, regardless of race, age, ethnicity, gender, disability, socioeconomic status, sexual orientation, or geographical location, to access high-quality and affordable health care services and support."<sup>10</sup> Behavioral health equity also means addressing the social determinants of health which impact our overall health, including education, transportation, housing stability, and employment and insurance status.

Historically, racial/ethnic and LGBTQIA+ communities experience obstacles in maintaining positive mental health. Our country's history of systemic racism negatively impacts mental health. Racism contributes to the unequal access to goods and services, which disproportionately affects those of diverse racial/ethnic backgrounds. The American Psychological Association has noted the mental health consequences of racial discrimination, including increased rates of depression, anxiety, suicidal ideation, post-traumatic stress disorder, and substance use.<sup>11</sup>



*Many caregivers could use more information on or help with caregiving topics. 62% of caregivers could use help with at least one topic.*

*– Caregiving In the U.S. 2020*

<sup>9</sup>U.S. Department of Health and Human Services. (2023, April 17). HHS finalizes policies to make coverage more accessible and expand behavioral health care access for millions of Americans in 2024. <https://www.hhs.gov/about/news/2023/04/17/hhs-finalizes-policies-make-coverage-more-accessible-expand-behavioral-health-care-access-millions-americans-2024.html>

<sup>10</sup>Substance Abuse and Mental Health Services Administration. (2023, May 25). Behavioral health equity. <https://www.samhsa.gov/behavioral-health-equity#:~:text=Behavioral%20health%20equity%20is%20the%20right%20to%20access,otherwise%20adversely%20affected%20by%20persistent%20poverty%20or%20inequality.>

<sup>11</sup>Novotney, A. (2023, May 18). Hate crimes are on the rise in the U.S. What are the psychological effects? American Psychological Association. <https://www.apa.org/topics/gun-violence-crime/hate-crimes>

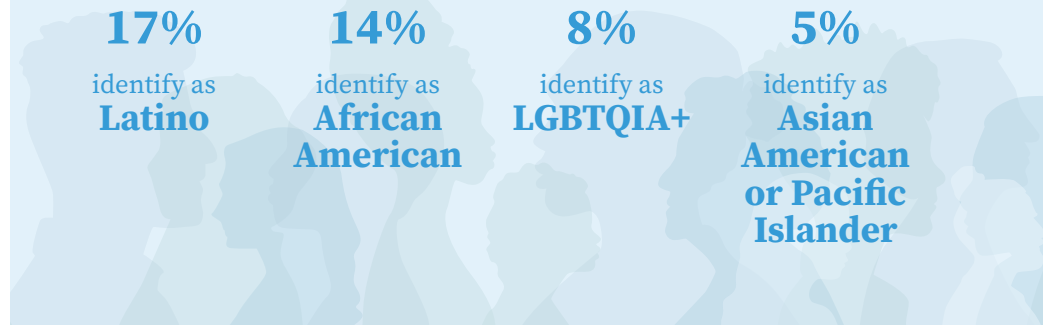


The effects of racism that these communities experience also affect their roles as caregivers. Often, providers aren't equipped with culturally-relevant nor linguistically-appropriate methods that allow them to understand the unique needs of caregivers of diverse racial/ethnic backgrounds. Increased advocacy and research are needed to bridge the gap between providers and diverse caregivers and to provide providers with the resources and tools to understand the historical inequities that have shaped the unique challenges, needs, and experiences of diverse caregiving communities.

- There is currently very little research on the caregiving experiences of those in the LGBTQIA+<sup>12</sup> community.<sup>13</sup> More LGBTQIA+ caregivers feel alone in their caregiving journey as compared to non-LGBTQIA+ caregivers which could lead to less overall support for these caregivers.<sup>14</sup> Due to a fear of discrimination, LGBTQIA+ caregivers are often prone to not disclose their LGBTQIA+ status to medical professionals, affecting their level of communication regarding their own health care needs as well as those of their care recipient. A great need for awareness and advocacy exists regarding the ongoing challenges that LGBTQIA+ caregivers face, including individual and institutional discrimination.
- Asian American and Pacific Islander (AAPI) caregivers receive less information from medical providers about caring for their care recipient as compared to non-Latino White caregivers.<sup>15</sup> The concept of filial piety, which is an attitude of respect and obligation to family elders, is prevalent in AAPI culture. This cultural norm may contribute to AAPI caregiver emotional stress as many AAPI caregivers feel that they have no choice in assuming their caregiving responsibility. The AAPI

*Often, providers aren't equipped with culturally-relevant nor linguistically-appropriate methods that allow them to understand the unique needs of caregivers of diverse racial/ethnic backgrounds.*

#### OF THE 53 MILLION CAREGIVERS IN THE U.S.\*:



community has reported that they would like increased guidance in navigating the health care system as well as tools for self-care, but this community receives less information from medical providers which could be attributed to language barriers.

- Latino<sup>16</sup> caregivers are often the sole caregiver for their care recipient, leaving them with few options for support.<sup>17</sup> Latino caregivers report significantly lower levels of psychological and physical well-being when caring for someone with dementia as compared to non-Latino White caregivers. Latino caregivers are 70 percent more likely to manage their care recipient's medication as compared to non-Latino White caregivers which contributes to higher levels of strain. There is a strong need for better support of Latino caregivers through policies and programs to address the factors that affect their caregiving responsibilities.
- Studies have found that African American caregivers are often the sole caregiver for their care recipient,

co-reside with their care recipient, earn less income, and work more hours as compared to non-Latino White caregivers.<sup>18</sup> These caregivers are less likely to receive information about managing care for their care recipient from their medical provider which is possibly attributed to racial bias in physician-patient relationships. This also affects the ability of African American caregivers to receive respite services. There is a need for more and better access to federally- and community-based programs to support African American caregivers.

<sup>12</sup>In *Caregiving in the U.S. 2020*, respondents identified as LGBT.

<sup>13</sup>National Alliance for Caregiving (2021, December). *Caregiving in a Diverse America: Beginning to Understand the Systemic Challenges Facing Family Caregivers*. [https://www.caregiving.org/wp-content/uploads/2021/11/NAC\\_AmgenDiverseCaregiversReport\\_FinalDigital-111821.pdf](https://www.caregiving.org/wp-content/uploads/2021/11/NAC_AmgenDiverseCaregiversReport_FinalDigital-111821.pdf).

<sup>14</sup>Ibid.

<sup>15</sup>Ibid.

<sup>16</sup>In *Caregiving in the U.S. 2020*, respondents identified as Hispanic or Non-Hispanic White.

<sup>17</sup>Ibid.

<sup>18</sup>Ibid.

\*The National Alliance for Caregiving and AARP. (2020, May). *Caregiving in the U.S. 2020*. Retrieved July 8, 2023, from [https://www.caregiving.org/wp-content/uploads/2020/06/AARP1316\\_RPT\\_CaregivingintheUS\\_WEB.pdf](https://www.caregiving.org/wp-content/uploads/2020/06/AARP1316_RPT_CaregivingintheUS_WEB.pdf).



An example of a policy that could be a step forward in achieving behavioral health equity is the **Equity in Mental Health Act (H.R. 1475)**. This legislation would provide funding to support research, improve the pipeline of culturally appropriate providers, build outreach programs that reduce stigma, and develop training programs to reduce disparities. This legislation passed the House of Representatives but has since stalled in the Senate. This proposal seeks to:

- Require the U.S. Department of Health and Human Services to establish a grant program to create interprofessional health care teams in areas with a high proportion of racial and ethnic groups and award grants that incorporate best practices that address mental health disparities in curricula for behavioral health professionals;
- Reduce stigma regarding mental health through outreach to racial and ethnic communities;
- Require studies on mental health disparities; and
- Reauthorize fellowship programs to support the education of mental health professionals who provide services to racial and ethnic communities.

Health care cannot exist in a silo without mental health care. Family caregivers, whether employed, retired, a veteran or those who only need coverage for a limited time, need access to mental health care that is on par with the same levels of service that they receive from providers who attend to their physical health needs.

## MENTAL HEALTH PARITY

Parity is the concept that mental health is covered in the same manner as physical health conditions. The coverage of benefits, treatment, and cost-sharing for mental health and substance abuse can't be more restrictive, more expensive, or less than those provided in medical/surgical benefits.

In 2008, the landmark Mental Health Parity and Addiction Act (MHPAEA) was passed.<sup>19</sup> This law called for mental health care benefits to be covered by health plans at the same level as physical health care benefits. Specifically, this law provided that large group health plans could not impose annual or lifetime dollar limits on mental health benefits that are not as favorable as those imposed on medical/surgical benefits. The law only applied to large group health plans and health insurance issuers that chose to include mental health/substance use

disorder (MH/SUD) benefits in their benefit packages.

This law was later amended by the Affordable Care Act of 2010 (ACA). The key changes made by the ACA were:<sup>20</sup>

- If a group health plan or health insurance coverage includes medical/surgical benefits and MH/SUD benefits, the financial requirements and limits on treatment cannot be more restrictive than the limitations that apply to “substantially all” medical/surgical benefits.
- MH/SUD benefits cannot be subject to separate cost-sharing requirements or treatment limits.
- If a group health plan or health insurance coverage includes medical/surgical benefits and MH/SUD benefits, and the plan provides for out-of-network medical/surgical benefits, the plan must also provide out-of-network MH/SUD benefits.
- Standards for medical necessity determinations relating to MH/SUD benefits must be disclosed upon request.

Ensuring access to mental health benefits has been a bipartisan focus since the passage of the MHPAEA, but this effort is often hampered by insurers. Insurers often make it difficult

to access mental health treatment. While federal and state laws require parity in mental and physical health care, mental health services are five times as likely to be out-of-network.<sup>21</sup> An estimated 45% of psychiatrists do not accept any form of insurance and a larger proportion only accept a limited set of plans which makes it difficult for patients to easily find in-network providers.<sup>22</sup> One survey found that only half of insured adults view their insurance plans as having adequate mental health coverage. Parity has been shown to decrease out-of-pocket costs and increase utilization for certain types of services, including admissions for substance abuse disorders.<sup>23</sup>

<sup>19</sup>Centers for Medicare & Medicaid Services. *The mental health parity and addiction equity act (MHPAEA)*. [https://www.cms.gov/CCIIO/Programs-and-Initiatives/Other-Insurance-Protections/mhpaea\\_factsheet](https://www.cms.gov/CCIIO/Programs-and-Initiatives/Other-Insurance-Protections/mhpaea_factsheet)

<sup>20</sup>*Ibid.*

<sup>21</sup>The White House. (2022, May 31). *Reducing the economic burden of unmet health needs*. <https://www.whitehouse.gov/cea/written-materials/2022/05/31/reducing-the-economic-burden-of-unmet-mental-health-needs/#~:text=The%20Federal%20Government%20covers%20some,from%20the%20U.S.%20Medicaid%20program>

<sup>22</sup>Center for Primary Care. (2020, December 15). *Here's why mental health care is so unaffordable & why Covid-19 might help change this*. Harvard Medical School. <https://info.primarycare.hms.harvard.edu/review/mental-health-unaffordable>

<sup>23</sup>The White House. (2022, May 31). *Reducing the economic burden of unmet health needs*. <https://www.whitehouse.gov/cea/written-materials/2022/05/31/reducing-the-economic-burden-of-unmet-mental-health-needs/#~:text=The%20Federal%20Government%20covers%20some,from%20the%20U.S.%20Medicaid%20program>



Many Americans are struggling to find and afford the mental health care that they need. Research has shown that individuals with private health insurance have a hard time finding a mental health provider.<sup>24</sup> To remedy this situation, the Biden-Harris Administration recently issued proposed regulations that would improve and strengthen mental health parity requirements and ensure that the millions of Americans with private health insurance can better access mental health benefits through their insurance plan. The proposed rule would:<sup>25</sup>

- Require health plans to make changes when they are not providing adequate mental health access. Health plans will need to ensure that people have equivalent access between their mental and medical benefits which will include an analysis of the plan's provider network, including a review of how much out-of-network providers are paid and how often prior authorization is required.
- Clarify what health plans can and cannot do. Health plans cannot use more restrictive prior authorization or narrower networks to make it harder for people to access MH/SUD benefits than their medical benefits.
- Close loopholes. This rule would close the MHPAEA loophole that did not require non-federal governmental health plans to comply with the MHPAEA's requirements. The rule would require more than 200 additional health plans to comply with the MHPAEA, providing protections to an additional 90,000 individuals.

Many Americans are struggling to find and afford the mental health care that they need.



In addition to regulations that would potentially strengthen mental health parity in the private insurance market, there are efforts to implement protections for those who rely on Medicare and Medicaid. **The Better Mental Health Care for Americans Act (S. 923)** is legislation that could potentially assist family caregivers by expanding mental health parity protections to Medicare Advantage, Part D, and to all Medicaid recipients.<sup>26</sup> This legislation seeks to apply parity protections across the health care system and strengthens penalties on insurance companies that don't abide by the rules.

This proposal would:

- Ensure that Medicare Advantage plans maintain accurate and updated provider directories;
- Increase reimbursement rates for Medicare and Medicaid;
- Increase accountability and oversight of integrated mental and behavioral health care under Medicare, Medicaid, and private health insurance plans; and
- Require Centers for Medicare and Medicaid Services to implement plans to better align payments, measure access and quality, and improve prevention services for mental and behavioral health.

<sup>24</sup>Fact Sheet: Biden-Harris Administration Takes Action to Make it Easier to Access IN-Network Mental Health Care <https://www.whitehouse.gov/briefing-room/statements-releases/2023/07/25/fact-sheet-biden-harris-administration-takes-action-to-make-it-easier-to-access-in-network-mental-health-care/>

<sup>25</sup>Ibid. See also: <https://www.federalregister.gov/documents/2023/08/03/2023-15945/requirements-related-to-the-mental-health-parity-and-addiction-equity-act>. The comment period on the proposed rule closes in October 2023.

<sup>26</sup>Better Mental Health Care for Americans Act, S. 923, 118th Cong. (2023). <https://www.congress.gov/bills/118th-congress/senate-bill/923/text>



## MENTAL HEALTH PROVIDER READINESS AND WORKFORCE DEVELOPMENT

The mental health workforce is comprised of several groups of providers. These professionals include:

- **Licensed Providers:** These providers have specialized training and are authorized by their respective state and professional board. Examples include psychologists, psychiatrists, primary care physicians, licensed clinical social workers, and nurse practitioners. Individuals with higher incomes often have greater access to these providers due to the issues related to low levels of insurance reimbursement and the concentration of these providers in more urban and affluent areas.
- **Clinical Supporters:** These providers also have specialized training and tend to focus on prevention and recovery, and sometimes partner with licensed providers. Examples include occupational therapists, nurses, addiction counselors, and recovery coaches. Clinical supporters generally focus on educating clients about their condition and aid in care coordination, patient advocacy, and the provision of social support. Reimbursement rates are lower for these providers as compared to licensed providers.
- **Community Care Workers:** These professionals interact with people in their community. These workers, also referred to as community health workers, work in a variety of clinical and community settings, serve as a liaison between health/social services and the community to facilitate access to services and improve the quality and cultural competence of service delivery. This type of work is typically grant funded and not covered by insurance. Even though there is an ample supply of community health workers, these professionals are sometimes hard to find due to a lack of sustainable funding options.
- **First Responders:** These workers are usually law enforcement personnel, school counselors, day care providers, emergency medical staff, and social service providers. These professionals usually have little to no training or support and their services are not reimbursable by insurance.

*“Mental health professionals will show up, police will show up. She doesn’t appear to be a harm to herself, see ya later!”*

*Boom, they leave.”*

*– Caregiver*

Even if individuals can afford mental health services, finding a provider can be another barrier that family caregivers must overcome when seeking mental health assistance. Additional barriers to services are linked to social determinants of health, including being in an under-resourced geographic area, being uninsured or underinsured, and lacking culturally and linguistically relevant care. Mental health care encompasses a wide variety of interventions delivered by a wide variety of professionals, but most of these professionals are in short supply in the United States. This shortage has been exacerbated by a historical lack of investment in behavioral health by Medicare and Medicaid, private insurers, and employers. As of 2021, 37% of Americans live in an area with mental health provider shortages, with two-thirds of these shortages in rural areas.<sup>27</sup>

There are several ways that the mental health workforce can be bolstered. This can potentially occur by removing the structural barriers that preclude individuals from diverse racial and ethnic groups from entering this workforce, addressing inequities in access for those living in rural areas, and creating financial incentives for the mental health workforce through the use of scholarships, loan forgiveness, and increased provider reimbursement.<sup>28</sup>

<sup>28</sup>The Commonwealth Fund. (2023, May 18). Understanding the U.S. behavioral health workforce shortage. <https://www.commonwealthfund.org/publications/explainer/2023/may/understanding-us-behavioral-health-workforce-shortage>

<sup>27</sup>The White House. (2022, May 31). Reducing the economic burden of unmet health needs. <https://www.whitehouse.gov/cea/written-materials/2022/05/31/reducing-the-economic-burden-of-unmet-mental-health-needs/#:~:text=The%20Federal%20Government%20covers%20some,from%20the%20U.S.%20Medicaid%20program>

The Mental Health Professional Workforce Shortage Loan Repayment Act of 2021 (S. 1578) would require the Health Resources and Services Administration to create a loan repayment program for mental health professionals who work in designated health professional shortage areas for a period of time in exchange for loan forgiveness. Each qualifying individual would receive a maximum of \$250,000.<sup>29</sup>

Another way to bolster this workforce is to build a more sustainable infrastructure for community health workers. COVID-19 put a spotlight on the ongoing lack of trust between historically marginalized communities, including racial/ethnic and LGBTQIA+ communities, and the government. Community health workers are a critical part of the health care system. They are trusted members of their community and can help to bridge the gap between patients, providers, and community/social supports and services. Systematic reviews and studies have documented that community health workers are effective in rural communities and can assist with chronic disease management and care for vulnerable populations, which can lead to reduced health care costs and health disparities.<sup>30</sup> Community health workers have been utilized to provide assistance with a wide range of mental health disorders, including depression, anxiety, trauma, and disruptive behavior disorders.<sup>31</sup>

The mental health workforce could also benefit through the development of policies that would incentivize health care providers through increased provider reimbursement rates. If reimbursement rates are increased, providers would be able to devote sufficient time to address caregiver mental health issues. One avenue to increase these rates is through the Physician Fee Schedule, which includes the fees that are used to reimburse physicians and other providers on a fee-for-service basis.

Another way to increase provider reimbursement is the development of HEDIS (Health Effectiveness Data and Information Set) bonuses that are tied to provider payments that would incentivize increased caregiver identification and screening. HEDIS is a performance improvement tool that includes more than 90 measures across six domains. However, low awareness exists among providers regarding reimbursement guidelines, tool terminology, and contractual payer obligations which add to the complexity of provider coding and billing.<sup>32</sup> Increased awareness among providers on mental health reimbursement issues is needed. Increased provider incentives stand to potentially ease mental health provider shortages by reducing provider burnout and can aid in the retention of mental health professionals.

### ADOPTION OF WHOLE HEALTH SYSTEM APPROACHES

A “whole health” approach is an integrated, person-centered model that focuses on incorporating patient’s goals into their health care. This interdisciplinary team-based approach aligns with a person’s life mission and addresses the social determinants that affect their health. A hallmark of this model is the creation of trusted patient-provider relationships. While the concept of “whole health” is not new, this type of health system approach is garnering increased attention and could positively aid family caregiver mental health due to its integrated approach.



Caregivers report performing medical lifesaving tasks with minimal training and monitoring. In July, the Centers for Medicare and Medicaid Services announced a proposed rule that, for the first time, would allow health care professionals to be reimbursed by Medicare *exclusively* for time spent training family caregivers who manage medications, assist care recipients with toileting and dressing, and oversee the use of medical equipment. The proposal covers both individual and group training. If this regulation is implemented, providers will finally be compensated for educating caregivers on how to perform these lifesaving tasks. This regulation stands to reduce caregiver anxiety and stress and improve the lives of care recipients. This proposed policy serves as an acknowledgment that policymakers understand and value the pivotal role that caregivers play each and every day.

<sup>29</sup>Mental Health Professionals Workforce Shortage Loan Repayment Act of 2021, S. 1578, 117th Cong. (2021), <https://www.congress.gov/bills/117/congress/senate-bill/1578>

<sup>30</sup>Association of State and Territorial Health Officials. Community health workers: Evidence of their effectiveness. National Association of Community Health Workers. <https://nachw.org/wp-content/uploads/2023/01/ASTHO-CHWs-summary-evidence-11-28-22-2.pdf>

<sup>31</sup>Barnett, M.L., Gonzalez, A., Miranda, J., Chavira, D.A., & Lau, A.S. (2018). Mobilizing community health workers to address mental health disparities for underserved populations: A systematic review. *Administration and Policy in Mental Health*, 45(2). Doi: 10.1007/s10488-017-0815-0.

<sup>32</sup><https://www.aapc.com/blog/85141-take-the-complexity-out-of-behavioral-health-coding/>





The National Academies of Science, Engineering, and Medicine (NASEM) was commissioned by the Department of Veterans Affairs (VA) and several other organizations to examine the VA's Whole Health System (WHS) approach and to create processes that accelerate the transformation of whole health care for veterans and the nation.<sup>33</sup> There has been a recent uptick in health system implementation of this concept.<sup>34</sup> The VA has been a leader in this arena and first implemented this type of health care model in 2018 in 18 VA sites, focusing on mental health, chronic pain, and disabilities.

The WHS paradigm is a shift from our current reactive, disease-oriented health care mindset to a more proactive approach centered on disease prevention, health, and well-being. Whole health systems are “cross-sectoral” and span health care, mental health, health behavior promotion, public health, community care, social services, built environment, education, religion, and the financial and economic sectors.<sup>35</sup>

The NASEM Committee found that the WHS model holds promise in not only improving patient health, but also in improving the health of health care workers and can potentially improve overall public health.<sup>37</sup> Reported benefits of the WHS model are increased access to care, reduced emergency room visits, improved patient experience and patient-reported outcomes. One recommendation was for the VA and the U.S. Department of Health and Human Services to lead the creation of a new Center for Whole Health Innovation, modeled after the Cancer Moonshot Initiative and the Centers for Medicare and Medicaid Services' Innovation Center. NASEM called for additional research and evaluation of the whole health model.

This approach holds promise in supporting the mental health of family

There are five defining characteristics of a whole health system:<sup>36</sup>

1. **People-Centered:** This approach emphasizes relationship-based care. People, family, and communities direct the goals of care.
2. **Comprehensive and Holistic:** This type of health care recognizes that the “whole” is more than the “sum” of its parts for the people, communities, and health systems that care for them. WHS utilizes conventional medical care which includes acute, chronic, preventive, reproductive, mental health, dental, vision, and hearing care, but also employs complementary, integrative health, and spiritual care.
3. **Upstream-Focused:** This requires a multisectoral, integrated, and coordinated approach to identifying and addressing the root causes of poor health. The root causes of poor health, also known as the social determinants of health, can include economic stability, housing, education, and social needs. Research shows that social determinants have a greater impact on health outcomes than conventional medical care.
4. **Equitable and Accountable:** Whole health care systems recognize their role in providing equitable care and being held accountable in providing care, as those not seeking care are often in the greatest need of care.
5. **Team Well-Being:** This approach recognizes that success of the WHS is built upon the interprofessional team's well-being. Burnout affects many health care professionals and the ability to care for others requires a stable and healthy team that can work to deliver the transformative care that the WHS seeks to provide.

caregivers. The VA included mental health professionals as part of its interprofessional WHS team when it implemented this model, thereby recognizing the importance of mental health in treating the “whole” person. Due to this model's expansive view of the care team, the whole health system approach stands to recognize and value the role of family caregivers as essential partners of the health care team of their care recipient. Research has found that when family caregivers are welcomed members of the patient's care team, it can improve continuity and care coordination and prevent hospital readmissions.<sup>38</sup> When caregivers are recognized for the level of care they provide, health care providers will no longer be allowed to dismiss the unmet mental health needs of caregivers.

This model can also aid caregivers by its examination of the needs of the whole person, their community, their

values, goals, and social determinants of health. The WHS model places an emphasis on building trust with patients which is important due to the history of discrimination against racial/ethnic and the LGBTQIA+ community.

<sup>33</sup>National Academies of Sciences. (2023, February). *Achieving whole health: A new approach for veterans and the nation - highlights*. [https://nap.nationalacademies.org/resource/26854/Whole\\_Health\\_Highlights.pdf](https://nap.nationalacademies.org/resource/26854/Whole_Health_Highlights.pdf)

<sup>34</sup>National Academies of Sciences. (2023, February). *Achieving whole health: A new approach for veterans and the nation*. <https://nap.nationalacademies.org/read/26854/chapter/1>

<sup>35</sup>Ibid.

<sup>36</sup>National Academies of Sciences. (2023, February). *Achieving whole health: A new approach for veterans and the nation - highlights*. [https://nap.nationalacademies.org/resource/26854/Whole\\_Health\\_Highlights.pdf](https://nap.nationalacademies.org/resource/26854/Whole_Health_Highlights.pdf)

<sup>37</sup>National Academies of Sciences. (2023, February 15). *U.S. should scale and spread whole health care through VA and HHS leadership, create federal center for whole health innovation, says new report*. <https://www.nationalacademies.org/news/2023/02/u-s-should-scale-and-spread-whole-health-care-through-va-and-hhs-leadership-create-federal-center-for-whole-health-innovation-says-new-report>

<sup>38</sup>Montesanti, S., MacKean, G., Fitzpatrick, K.M., & Fancott, C. (2023). *Family caregivers as essential partners in care: Examining the impacts of restrictive acute care visiting policies during COVID-19 pandemic in Canada*. *BMC Health Services Research*, 23(320). Doi: 10.1186/s12913-023-09248-3.

## CONCLUSION

The time is ripe for increased advocacy and dialogue that prioritizes the mental health needs of family caregivers - the 53 million-person strong, unpaid workforce caring for a family member, friend, or neighbor with health care needs or functional disabilities. This often “invisible” segment of society is balancing multiple needs – the needs of their care recipient, their own needs, and their health, work and family responsibilities, all of which take a toll on their mental health. To address issues surrounding the mental health of family caregivers, NAC supports the following recommendations that build on emerging policy areas.



## BEHAVIORAL HEALTH EQUITY

- **Recommendation:** Increase funding to support research on the mental health needs of caregivers with diverse backgrounds, including race/ethnicity, income, and LGBTQIA+ status, and encourage the development of culturally-relevant training tools for health care professionals.

## FAMILY CAREGIVER MENTAL HEALTH RESEARCH

- **Recommendation:** Increase federal and private sector funding opportunities for researchers to develop, evaluate, and scale caregiver mental health interventions across communities and health care systems.
- **Recommendation:** Establish an Office of Caregiver Research within the National Institutes of Health's Division of Program Coordination, Planning, and Strategic Initiatives to provide a centralized place to plan for caregiving interventions, observational studies such as caregiver cohort studies, and the design of hospital-based caregiver registries. This coordinating office can help prioritize and inform research on the mental health of family caregivers across federally funded research, including the National Institute of Mental Health.

## MENTAL HEALTH PARITY

- **Recommendation:** Expand mental health parity protections for family caregivers by expanding mental health parity protections in Medicare Advantage, Part D, and to all Medicaid recipients.

## MENTAL HEALTH PROVIDER READINESS AND WORKFORCE DEVELOPMENT

- **Recommendation:** Health care providers need to be reimbursed at levels that incentivize them to take the time to examine caregiver mental health and discuss these issues with their patients. Providers should also have access to increased training opportunities to learn more

about family caregiver issues, making health care less fragmented and more person-centered.

- **Recommendation:** Increase programs that will encourage individuals to enter the mental health field through scholarships and loan forgiveness and efforts should be made to examine ways to create sustainable funding streams for community health workers.

## ADOPTION OF WHOLE HEALTH SYSTEM APPROACHES

- **Recommendation:** The Health Resources and Services Administration, building on its existing health center program, should take the lead in scaling and spreading whole health care in the community.
- **Recommendation:** Increase funding for additional research on Whole Health System approaches, particularly, the use of mental health professionals in this model and the development of innovative tools and services that could be utilized to screen, assess, and treat and the holistic needs of family caregivers.

A foundational step in uplifting and addressing the needs of family caregiver mental health is the acknowledgment that caregiver mental health **matters**. Caregivers aren't often part of the national dialogue on health care or other social issues which means that their mental health needs are often overlooked. Family caregiver mental health should be integrated into national caregiver strategies and in other public discourse where issues related to loneliness, isolation, anxiety, fatigue, and other mental health and public health conditions are discussed. When the needs of family caregivers are taken out of the shadows and discussed more openly and frequently, caregiver mental health will assume a position of prominence and actionable solutions to these issues will be developed. NAC hopes that this brief sheds light on this important topic and we urge you to take steps to learn more about the mental health needs of caregivers.

*If you would like to learn more about the National Alliance for Caregiving's advocacy efforts in improving the lives of family caregivers, as well as join us while we work to advance the mental, emotional, social and equitable needs of family caregivers, you can join our Act on RAISE campaign here: [actonraise.org/join-us/](https://actonraise.org/join-us/).*

## Acknowledgements



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Kristi Guillory Reid is an independent consultant with over 20+ years of experience and success in policy research and design, program management, stakeholder engagement, strategic planning, and communications. Kristi has a proven aptitude in developing sophisticated policy and advocacy strategies for national organizations to advance constituent and stakeholder engagement and legislative priorities. She has demonstrated experience in assisting organizations with bolstering diversity, equity, and inclusion (DEI) efforts to foster inclusivity, building more diverse teams, and promoting DEI as a strategic business priority. For more information about Kristi's expertise and services, please visit: [kristiguilloryreid.com](http://kristiguilloryreid.com).



### ABOUT THE NATIONAL ALLIANCE FOR CAREGIVING

Established in 1996, the National Alliance for Caregiving is a non-profit coalition of national organizations focusing on building health, wealth, and equity for family caregivers through research, innovation, and advocacy. We envision a society that values, supports, and empowers family caregivers to thrive at home, work, and life. Learn more at [caregiving.org](http://caregiving.org).

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