



**AMERICAN
PSYCHOLOGICAL
ASSOCIATION**
SERVICES, INC.

Written Testimony for the Record Submitted by:

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to the United States Senate Special Committee on Aging
Field Hearing—From Infancy to Aging: The Effects of Caregiving Across the Lifespan

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On behalf of the American Psychological Association Services (APA Services), please accept the following written comments for the consideration of the Senate Special Committee on Aging for its Field Hearing titled “From Infancy to Aging: The Effects of Caregiving Across the Lifespan”. APA Services is the companion organization of the American Psychological Association, which is the nation’s largest scientific and professional nonprofit organization representing the discipline and profession of psychology, as well as over 157,000 members and affiliates who are clinicians, researchers, educators, consultants, and students in psychological science. Through the application of psychological science and practice, our organization’s mission is to have a positive impact on critical societal issues.

Mental Health Impact of Caregiving

APA Services applauds this Committee’s focus on the mental health of caregivers. In 2021, an estimated 38 million family caregivers provided some form of unpaid care to an adult experiencing permanent or temporary limitations in their ability to perform everyday activities of living like mobility, eating, or bathing.¹ The specific nature of the assistance furnished by caregivers varies by the nature and degree of the person’s condition.² For example, individuals recently discharged from hospital settings may need caregivers to assist with adherence to post-discharge protocols like medication or diet. Older adults are also more likely to experience conditions that result in fluctuating and potentially diminished capacity for decision making, namely post-operative delirium and other neurocognitive disorders, which can necessitate caregiver assistance with daily activities including managing finances or use of prescription medications. Those with disabilities may require caregivers to assist with various activities of daily living (ADLs) or transportation. People with serious mental health needs may require caregivers to monitor their well-being and safety. In addition to these direct care tasks, many caregivers also assume a care coordination role that could include addressing problems with health insurance coverage or communicating with multiple providers about implementing plans of care.

Through their unreimbursed efforts, caregivers contribute a total of approximately \$600 billion to the U.S. health care system. However, the fact that a caregiver provides services to a loved one without expectation of compensation does not mean that caregiving is entirely “free.” Indeed, there is ample evidence of its physical and mental toll on caregivers. Caregiving is generally associated with higher

¹ AARP Public Policy Institute (March 2023). Valuing the Invaluable: 2023 Update.

<https://www.aarp.org/content/dam/aarp/ppi/2023/3/valuing-the-invaluable-2023-update.doi.10.26419-2Fppi.00082.006.pdf>.

² Reinhard, Susan, Heather M. Young, Carol Levine, Kathleen Kelly, Rita Choula, and Jean Accius. *Home Alone Revisited*. Washington, DC: AARP Public Policy Institute, April 2019 <https://doi.org/10.26419/ppi.00086.001>.

levels of risk for chronic health conditions like coronary heart disease³, increased inflammation⁴, and accelerated aging of the caregiver's immune system.⁵ There is also evidence that caregivers are generally more likely to neglect their own health and forego preventative care for their own medical needs.⁶

The mental health impacts of caregiving tell a similar story. While caregivers may experience some degree of personal psychological fulfillment and meaning through their efforts⁷, caregivers also are more likely to report higher levels of anxiety and depression than their non-caregiver counterparts.⁸ In addition to the obvious physical and mental strain from providing direct support, caregivers experience additional stressors that can contribute to this phenomenon. With 61% of caregivers under employment, caregivers may experience stress from balancing their work-related demands with those at home.⁹ Caregivers may also be struggling with balancing care for the older adult with caring for other family members, as 30% of caregivers reside in multi-generational households with children or grandchildren.¹⁰ Caregivers for patients with dementia, for example, may be coping with their own sense of anticipatory bereavement of losing their loved one or a deterioration of the relationship due to any cognitive or behavioral manifestations of the disease.¹¹

Evidence-Based Caregiver Training

Caregivers are rarely, if ever, asked whether they are prepared for their new caregiving role. Instead, they are frequently thrust very quickly into caregiving situations with little notice and limited training as to the complicated tasks they are expected to perform as part of this role. Unfortunately, this lack of mastery of caregiving tasks only serves to amplify the anxiety and depression that caregivers may already be experiencing.¹²

³ Haley WE, Roth DL, Howard G, Safford MM. Caregiving strain and estimated risk for stroke and coronary heart disease among spouse caregivers: differential effects by race and sex. *Stroke*. 2010 Feb;41(2):331-6. doi: 10.1161/STROKEAHA.109.568279. Epub 2010 Jan 14. PMID: 20075357; PMCID: PMC2818824.

⁴ Allen A. P., Curran E. A., Duggan Á., Cryan J. F., Chorcóráin A. N., Dinan T. G., ... Clarke G (2017). A systematic review of the psychobiological burden of informal caregiving for patients with dementia: Focus on cognitive and biological markers of chronic stress. *Neuroscience and Biobehavioral Reviews*, 73, 123–164. doi:10.1016/j.neubiorev.2016.12.006

⁵ Mausbach, B. T., Patterson, T. L., Von Känel, R., Mills, P. J., Dimsdale, J. E., Ancoli-Israel, S., & Grant, I. (2007a). The attenuating effect of personal mastery on the relations between stress and Alzheimer caregiver health: A five-year longitudinal analysis. *Aging & Mental Health*, 11, 637–644.

⁶ Schulz, R., Newsom, J., Mittelman, M., Burton, L., Hirsch, C. & Jackson, S. (1997). Health effects of caregiving: The Caregiver Health Effects Study: An ancillary study of The Cardiovascular Health Study. *Annals of Behavioral Medicine*, 19, 110-116.

⁷ Miller, B. Adult Children's Perceptions of Caregiver Stress and Satisfaction. *Journal of Applied Gerontology* 8, no. 3 (1989): 275–93

⁸ Beach, S. R., Schulz, R., Yee, J. L., & Jackson, S. (2000). Negative and positive health effects of caring for a disabled spouse: Longitudinal findings from the Caregiver Health Effects Study. *Psychology & Aging*, 15 (2), 259-271. doi:10.1037//0882-7974.15.2.259.

⁹ AARP and National Alliance for Caregiving. *Caregiving in the United States 2020*. Washington, DC: AARP. May 2020. <https://doi.org/10.26419/ppi.00103.001>

¹⁰ Id.

¹¹ Ascher EA, Sturm VE, Seider BH, Holley SR, Miller BL, Levenson RW. Relationship satisfaction and emotional language in frontotemporal dementia and Alzheimer disease patients and spousal caregivers. *Alzheimer Dis Assoc Disord*. 2010 Jan-Mar;24(1):49-55. doi: 10.1097/WAD.0b013e3181bd66a3. PMID: 20220322; PMCID: PMC2838197.

¹² Chan EY, Glass G, Chua KC, Ali N, Lim WS. Relationship between Mastery and Caregiving Competence in Protecting against Burden, Anxiety and Depression among Caregivers of Frail Older Adults. *J Nutr Health Aging*. 2018;22(10):1238-1245. doi: 10.1007/s12603-018-1098-1. PMID: 30498832; PMCID: PMC6302747.

Caregiver Behavior Management Training (CBMT) helps fulfill this unmet need of caregivers. CBMT is provided to parents or caregivers of multiple patients simultaneously, teaching interventions that caregivers can independently use to better manage the patient's disease. Behavioral training associated with this service requires the clinical expertise of at least one psychologist or qualified health care professional (QHP) who is well versed in evidence-based behavior management procedures and strategies.

This has the effect of multiplying the impact of treatment, serving more individuals while utilizing fewer clinical hours. In other words, more patients are helped by fewer providers over less time when compared to individual or family therapy treatment sessions. For example, providing a 60-minute group caregiver behavior management service for five patients over 12 sessions would result in 720 minutes of direct patient care, compared to treating five patients with family therapy for 12 sessions, which would result in 3,600 minutes of direct patient care. This efficiency improves access to care for patients and ultimately results in cost savings for the health care system.¹³ These services are also known to delay the necessity of nursing home placements for older adults with dementia, allowing patients to remain in their own homes over a longer span of time.¹⁴

APA Services applauds the Centers for Medicare and Medicaid Services (CMS) for activating a new coding and reimbursement mechanism for CBMT services provided by psychologists and other QHPs (CPT Codes 96202/96203) in its annual Medicare Physician Fee Schedule proposed rule. APA Services also applauds CMS for allowing such services to be furnished via telehealth, enabling access for the many caregivers who cannot travel to an in-person clinical setting due to their own or the patient's circumstances. APA Services calls on members of the Committee to support this proposed rule and to facilitate similar coverage of these services in Medicaid and Marketplace plans.

Prompt Access to Evidence-Based Treatment

Of course, adequate training will not entirely eliminate the need for individual mental or behavioral health care for some caregivers. Congress must make it a priority to facilitate access to mental and behavioral health services for caregivers and other individuals who may be struggling with an unmet mental or behavioral health need. The acceptance and use of telehealth (including telehealth furnished via audio-only interactions) for treatment of mental and behavioral health services, for example, remains a popular option for patients and practitioners alike.¹⁵ In some cases, the decision of patients and providers to use telehealth may have superior clinical benefits over their in-person counterparts; for example, psychologists treating patients via telehealth may gain insights into the patient's personal living environment or patients may feel more comfortable accessing treatment from the comfort and safety of their own homes.

Congress is faced with critical decisions before the end of this year on whether to continue this forward momentum on access to tele-mental and tele-behavioral services. Fortunately, Congress decided to permanently allow Medicare beneficiaries to receive mental health services via telehealth from their own homes in the Consolidated Appropriations Act of 2021; however, it also imposed a requirement that

¹³ Sansoni, J., Anderson, K. H., Varona, L. M., Varela, G. (2013). Caregivers of Alzheimer's patients and factors influencing institutionalization of loved ones: some considerations on existing literature. *Annali di Igiene: Medicina Preventiva e di Comunità*, 25(3), 235-46. doi: 10.7416/ai.2013.1926. PMID: 23598807

¹⁴ Mittelman, M. S., Haley, W. E., Clay, O. J., Roth, D. L. (2006). Improving caregiver well-being delays nursing home placement of patients with Alzheimer disease. *Neurology*, 67(9), 1592-9. doi: 10.1212/01.wnl.0000242727.81172.91. PMID: 17101889.

¹⁵ See, e.g., Bartelt K, Piff A, Allen S, Barkley E. Telehealth Utilization Higher Than Pre-Pandemic Levels, but Down from Pandemic Highs. Epic Research. <https://epicresearch.org/articles/telehealth-utilization-higher-than-pre-pandemic-levels-but-down-from-pandemic-highs>. Accessed on July 12, 2024.

Medicare beneficiaries must be seen in-person by the provider for continued coverage of their telehealth services.

Congress should reconsider and repeal the “in-person visit” requirement. Patients seeking mental health services already face several obstacles to treatment, including but not limited to social stigma, complicated insurance coverage policies, and practical difficulties like transportation. Imposing an arbitrary and uniform in-person visit requirement increases the likelihood that patients will simply discontinue treatment altogether. Rather than discouraging fraudulent claims, this policy will instead discourage many more legitimate claims for treatment. Additionally, the fact that the in-person visit only applies to mental health services further perpetuates a bias against coverage of mental and behavioral health treatment in Medicare and other insurance coverage programs.

APA Services calls on members of the Committee to adopt a permanent solution, such as the **Telemental Health Care Access Act (H.R. 3432)**, that would ensure Medicare beneficiaries’ continued access to the broad range of mental and behavioral health services via telehealth without unnecessary and arbitrary barriers to treatment. Given the political dynamics of a Presidential election year, however, we understand that Congress may need additional time to make this decision. APA Services acknowledges that a two-year extension of the current Medicare coverage rules, such as that offered in the Energy & Commerce Committee’s forthcoming markup of the Telehealth Modernization Act (H.R. 7623), may be necessary as a short-term solution. However, we ask Congress to make a longer-term decision by the end of that extension; patients require stability in their ability to access mental and behavioral health treatment remotely.

There are also innovative and evidence-based models of integrating behavioral health treatment into primary care practices, such as the Primary Care Behavioral Health (PCBH) model and the Collaborative Care model (CoCM), as well as models that blend different features of PCBH and CoCM based on the resources available in their local community. There is ample evidence that integrated care can result in cost savings across the health system, since behavioral comorbidities can lead to medical costs for physical conditions that are two to three times higher than incurred for patients without behavioral health conditions.¹⁶ These benefits are especially felt in rural and underserved areas where the local primary care clinic is the default health care system. However, despite its potential, a number of barriers exist to practitioner adoption of integrated care.¹⁷ These include additional clinical and administrative staffing costs, adequate reimbursement for increased interprofessional consultation, education, and training, changes to primary care practices’ operating procedures, upgrades or modifications to physical office spaces, and investments in information technology systems.

To help practitioners overcome these barriers, APA Services urges members of this Committee to support the **COMPLETE Care Act (H.R. 5819 / S. 1378)**. This bill would temporarily boost Medicare reimbursement rates for certain integrated care codes to aid in the up-front adoption costs, require CMS to provide technical assistance to primary care practices seeking to adopt evidence-based behavioral health integration models, and require CMS to establish quality measurement reporting requirements for behavioral health integration services within existing Medicare alternative payment models. Last

¹⁶ See, e.g., Ross, K. M., Klein, B., Ferro, K., McQueeney, D. A., Gernon, R., & Miller, B. F. (2019). The cost effectiveness of embedding a behavioral health clinician into an existing primary care practice to facilitate the integration of care: A prospective, case-control program evaluation. *Journal of Clinical Psychology in Medical Settings*, 26, 59-67 (finding that integrating a psychologist into a primary care practice resulted in cost savings of \$860 per member per year).

¹⁷ Hartnett, T., Loud, G., Harris, J., Curtis, M., Hoagland, G.W., Serafini, M., Glassberg, H., Chung, H. (2023). *Strengthening the Integrated Care Workforce*.

Bipartisan Policy Center. <https://bipartisanpolicy.org/report/strengthening-the-integrated-care-workforce/>

December, the Senate Finance Committee voted 26-0 to approve key provisions of the COMPLETE Care Act as part of the Better Mental Health Care, Lower-Cost Drugs, and Extenders Act of 2023.

Robust Support for Key Caregiving Programs

Many federal programs provide a key supplement to services provided by clinicians. Area Agencies on Aging (AAAs) and Aging and Disability Resource Centers (ADRCs) serve as a critical hub for services to older adults and adults with disabilities. For example, the National Family Caregiver Support Program provides grant funding to an array of supports to caregivers—including those that are non-clinical in nature. Services commonly provided under this program include information about services available to caregivers in the community, navigation to accessing these services, individual caregiver counseling (including support groups and caregiver training), and temporary respite care. However, important programs like this are set to expire at the end of the current fiscal year due to the expiration of the Older Americans Act. APA Services calls on members of this Committee to support a robust reauthorization of this critical piece of authorizing legislation.

Further research is also a necessary means of developing new innovations in caregiver support. The National Institute on Aging (NIA) was founded in 1974 within the National Institutes of Health (NIH) to support research on the health of older adults. NIA-supported research provides the foundation for scientific advancements in the field of gerontology, including family caregivers' contributions. Funding for key research at NIA would include research on caregivers' needs and how best to address issues specific to caregivers. APA Services asks members of this Committee to continue its support for robust funding of NIH at \$51.303 billion for FY 2025 and commensurate increases in NIA funding.

APA Services appreciates the Committee's efforts to ensure that the invaluable efforts of caregivers are not lost due to physical or mental health challenges. We are eager to work with this Committee and its members to develop legislation that would accomplish this goal. If you have any questions, please feel free to reach out to Serena Davila, Senior Director of Congressional and Federal Relations, at SDavila@apa.org.